# VULNERABLE PARENTING

## A STUDY ON PARENTS WITH MENTAL HEALTH PROBLEMS: STRATEGIES AND SUPPORT

P.C. VAN DER ENDE

# Vulnerable parenting

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## Colophon



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## A STUDY ON PARENTS WITH MENTAL HEALTH PROBLEMS: STRATEGIES AND SUPPORT

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# CHAPTER 1

## GENERAL INTRODUCTION

> **Amanda is a 31-year-old single mother suffering from an anxiety disorder who was admitted to a psychiatric hospital. She was sent home recently and, with an expert by experience, tries to pick up her life in a personal recovery process. In the period before her stay in the hospital, she could barely handle her eleven-year-old daughter and eight-year-old son. She now has joined a parenting program and is supported by a social worker to develop competencies to raise her children.**

> **Lex is a 35-year-old man with bipolar disorder. He and his wife were separated three years ago. Together they have a five-year-old son, Kevin, who lives with his mother for the majority of time. Once a fortnight and during three weeks in the summer, Kevin goes to his father. Lex's ex-wife stimulates the contact between Kevin and Lex but the latter finds it difficult to have the energy for Kevin' s care and make a real connection as a father.**

The stories of Amanda and Lex illustrate frequently experienced dilemmas for parents with mental health problems on how to fulfill a parental role in combination with coping with psychiatric problems, having a social life and daily activities. Amanda and Lex are not the only ones…

This thesis encompasses a series of studies on parenting by parents with mental health problems[1]. The main themes are the strategies that are used in handling mental health problems in combination with raising children and the informal and professional support occasionally needed.

1 The expression 'mental health problems' is preferred in this thesis; in the context of other authors or journals, 'mental illness' or 'psychiatric disabilities' are used. These concepts have the same meaning in this thesis.

This introduction gives an overview of research on parents with mental health problems, the support needed, the prevalence of these parents and the challenges they face. Recovery and psychiatric rehabilitation are leading concepts in this thesis; how people with mental health problems cope with their role as a parent is shown from these perspectives. A special focus lies on those parents who experience enduring constraints because of the severity and multifaceted impact of their mental health problems. At the start of the work that laid the foundation for the studies presented in this thesis, the choice for this group of parents with severe mental illness (SMI) was made. This group includes all patients who, as a consequence of a psychiatric illness experience severe and complex problems with functioning in different areas of their lives for an (expected) period of at least two years. These patients often suffer from psychotic episodes, severe bipolar disorders and other severe Axis I and Axis II disorders. Many times these patients are treated in separate 'long-term' care programs (Mulder et al., 2010).

Rehabilitation workers from several mental health organizations found that apart from the needs of achieving goals concerning the usual life domains (i.e., living situation, daily activities, work, education, and social contacts), some people with severe mental illness expressed the need for support in identifying ways to fulfill their parenting role more adequately and satisfactorily. This finding prompted the administration of a brief explorative survey to learn the needs of parents with mental health problems and consequently, to develop a program to support such parents. Based on the resulting program, "Parenting with Success and Satisfaction," a psychiatric rehabilitation and recovery-based, guided self-help intervention for parents with severe mental illnesses (see Appendix 2).

At the start of the evaluation study (Chapter 5), which was a pilot study of the effect of the program, four experienced researchers assumed that training 100 professionals would yield at least 50 participants in the intervention group. However, only 11 parents participated after an inclusion period of one and a half years, with 15 parents in the other group. The outcomes of the evaluation study were published with the data of the 26 parents to discern the suitability of the outcome measures and to indicate possible changes in parental skills and satisfaction due to the program in contrast to the typical approaches of mental health workers. Next, a qualitative study was conducted to gain insight into the threshold of requesting support on parental issues. This study should also illuminate how people with SMI cope with the challenges of parenting, with or without (in) formal help.

## Needs to the parental role

For people who have children, parenting is one of the most important social roles. This statement is most likely also true for people with mental health problems. Being burdened with mental health problems also has extra consequences for material, psychosocial and physical needs. Negative consequences can be found regarding:

- income, work, housing and possibilities for transport (Mowbray, Oyserman, Bybee, MacFarlane & Rueda-Riedle, 2001); i.e. many of these parents do not have payed full time jobs and must live on a minimum or low income which makes life extra harsh for them in general but especially with parental responsibilities.
- childcare and housekeeping; in line with the financial problems Barker & Maralani (1997), who executed a secondary analysis of the US Census Bureau Survey of income and Program Participation, reported that a majority of the parents with mental health problems are not in a situation to get support in terms of childcare or housekeeping because of a lack of finances to pay for these.
- the possible array of parental and other activities such as recreation and celebrating holidays; because of a lack of energy as a result of the mental health problems these parents report that they sometimes do not have the stamina that it takes to initiate these extra activities (Barker & Maralani, 1997). Also, psychiatric symptoms increase the stress in parenting (Kahng, Oyserman, Bybee, Mowbray, 2008) and parents can feel that they have no energy left to be active in other areas of life, besides the parental role.

Other needs for support mentioned in the literature:

- to cope with psychiatric symptoms and the side effects of medication. Howard & Kumar (2001) mentioned the specific needs for support dealing with the disorder and medication and drug consumption in the context of parental tasks.
- during the mourning process when the mental health problems have led to the loss of parental responsibilities and/or loss of contact with children to a foster family or ex-partner (Haans, Robbroeckx, Hoogeduin & Van Beem-Kloppers 2004; Zeitz, 1995).

Whereas this enumeration shows that, at least in the literature, there is awareness that parents with mental health problems do experience difficulties raising their children in various ways, the parental role is not so often a topic as such in mental health care. And if this is the case, it is not clear whether the support offered matches the needs of the parents involved.

People with mental health problems often need pharmacological and psychological treatment. In addition to the need for treatment, many parents require support in their daily functioning to fulfill valued roles within their family and in the community. In the US and the UK, knowledge on strategies and support programs for parents with mental

health problems has been developed since the 1990s (Nicholson, Nason, Calabresi & Yando, 1999; Mowbray, Oyserman, Bybee, MacFarlane & Rueda-Riedle 2001; Nicholson & Friesen, 2014). In the Netherlands, only recently there has been a structural focus on the parenting task by parents with mental health problems (for example, Jonkers, 1995; Van Weeghel, 2005; Van der Ende & Venderink, 2006, see Appendix 1; Wansink, Hosman, Janssens, Hoencamp, & Willems, 2014).

In earlier times the combination of having mental health problems and having children mostly raised questions about competences and vulnerability (Mowbray et al. 2001). However, in recent decades, the focus of research shifted from stressing the adverse effects of parental mental health problems on the well-being of the children involved to consideration of the experience and needs of mothers and fathers living with mental health challenges and to the development of strategies to support their integration into family and community life (Nicholson et al. 1999).

Whereas the literature indicates a growing awareness that parents with mental health problems experience various difficulties in parenting, the parental role is not a common topic as such in mental health care. First, patients must be recognized as parents, and communication must be initiated concerning the possible constraints and needs for support. Parents, however, report reluctance in sharing their experiences because they fear reinforcing the societal stigma and sometimes stigma from formal care providers, who already regard them as unfit parents unable to adequately care for educate their children (Howard & Kumar, 2001; Nicholson & Henry, 2003). Moreover, if a request for assistance or advice is expressed, the support offered does not necessarily match the needs of the parents. For instance, Ackerson (2003) found that in cases in which problems are identified, parents report that professionals in mental health care can sometimes assume excessive control of nurturance and other life tasks. Fear of losing custody can be a reason to avoid care and more specifically, support for parenting (Howard & Kumar, 2001) and, when in contact with mental health workers, can form a barrier for open communication. In another context Van der Pas (2006) points out that in contact with professional care, parents can miss the recognition of the daily difficulties of parenting and the legitimization of sometimes failing as a parent. Unwanted advice and support that does not accord with the needs of the parents increases the risk of isolation of these parents. This statement also holds true in the case of relatives, who typically can be a first source of support (Van Weeghel, 2007). Whereas family members may assume a key role in times of crisis, this role can also increase stress levels and does not guarantee optimal support in the long-term (Ackerson, 2003).

## Epidemiological data of people with Severe Mental Illness who have children

In the United States, approximately two-thirds of the people who meet the criteria for severe mental illness (SMI) and who live in the community have had children (Nicholson, Biebel, Williams & Katz-Leavy, 2004). In Australia, it has been estimated that 21 to 23% of all children live in families with at least one parent with a mental illness (Reupert & Mayberry, 2011). In the Netherlands, information on this subject is available from sheltered housing organizations. In a study by De Heer-Wunderink, Caro-Nienhuis, A.D., Sytema, S. & Wiersma (2007), 26% of people with SMI living in supported or sheltered housing were found to have one or more children. More information about prevalence will be discussed in chapter 2 of this thesis.

Having a mental illness can lead to the loss of the custody of one's children. However the figures are inconclusive as to absolute chances of out-of- home placements. For the broad group of all parents with mental illness, Dipple, Smith, Andrews & Evans (2002) found that in the UK 68% were separated from their children for at least one year. In the case of mothers with the diagnosis of schizophrenia, in the UK the group who loses custody of their children is also almost 70% (Seeman, 2012). In Denmark the figures are not as high: in a study conducted by Ranning, Thorup, Hjorthøj & Nordentoft (2015) based on the national Register it appeared that 40% of the children of mothers with schizophrenia were placed out of their homes. For the USA only figures on the total group of parents with severe mental illness are available: in a study published in the nineties approximately 60% of parents in this group were found to have lost custody of their children (Coverdale & Aruffo, 1989). For the Netherlands, we only have an indication that the average number of out-of-home placements related to parents with SMI lies at the same level as all out-of-home placements in the US (Knorth & Koopmans, 2012).

## Stigma on parenting and mental health problems

Stigma has a special meaning for people with mental health problems who are parents. Jeffery et al. (2013) reported that 22.5% of people with mental health problems felt discriminated against in starting a family, and 28.3% felt discriminated against in their parental role. Additionally, society views people with mental health problems as unfit to raise children (Nicholson & Henry, 2002). Thornicroft, et al. (2009) executed a cross-sectional survey in 27 countries in which 732 participants with schizophrenia were interviewed. Having the diagnosis of schizophrenia and acting as a parent was answered by 12% as a disadvantage, 15% as indifferent and 70% as not applicable. For people with depression comparable answers are given (Lasalvia et al. 2012). The consequences of stigma and discrimination are a barrier for parents to be open about their mental health problems and ask for support or treatment. People feel that they are considered unfit parents who cannot be responsible for making decisions. In addition, children of parents with mental health problems are vulnerable to discrimination. Fear of stigmatization

often leads to secrecy and concealment, leading to a lack of sometimes badly needed social support (Hinshaw, 2005; Thornicroft et al. 2009). In a national cross-sectional survey among a representative panel of the Dutch population more than half of the respondents (N=2793) agreed that, in case of addiction, people should be forbidden to care for children (Van Boekel, Brouwers, Van Weeghel & Garretsen, 2013). Due to fear of stigmatization, many children of parents with a mental illness tend to be silent about their home situation (Hinshaw, 2004).

One of the consequences of stigmatization and discrimination is a diminishing willingness to seek professional support and receive treatment (Howard, Kumar & Thornicroft, 2001). On the other hand, when stigmatized parents do seek and obtain support, they often find that professionals exert too much control in raising their children and in performing other life tasks (Ackerson, 2003a).

## Children of parents with mental illness (COPMI)

Mental illness affects not only the individual; when a parent has a mental illness, the effects are also felt by other family members and, in particular, his or her children. The well-being of the children is a first priority of the Convention on the Rights of the Child (CRC, Article 3/1, 1989); “In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration”. Although the focus of this study lies on the parental role from the parents’ point of view, in this paragraph, the children’s point of view is described to reveal some of the consequences for children of a parental mental illness.

There are several additional risks experienced by Children of Parents with Mental Illness (COPMI). For one of developmental problems of these children due to genetic heritability and the dysfunctional biological processes caused by maternal stress during pregnancy and psychosocial stress during a child’s development (Van Santvoort, Hosman, Van Doesum & Janssens, 2013). Also, chances are that these children miss safety and a sense of security in their early years. Several studies have shown that children of parents with mental illness are at higher risk of developing a mental illness themselves (Brok & Van Doesum, 1998; Vollebergh et al., 2003; Landman-Peeters, 2007; Mesman, 2015). Children are at risk of being exposed to familial and contextual stressors associated with parental mental illness such as neglect, marital conflicts, divorce, domestic violence, stigmatization and isolation. Some of these children grow up very quickly and must execute grown-up tasks, which is called parentification. Such children may be engaged in situations that exceed their capabilities, for example, responsibility for the household or a lack of emotional support from a parent (Venderink & Van der Ende, 2006).

In the last 25 years, several organizations have developed programs that offer support and information particularly for the COPMI (Reupert et al. 2013). To reduce the risk for these children and enhance their resilience, preventive interventions have been developed in various countries. The most frequently offered standardized interventions are support groups in which children of mentally ill and/or addicted parents meet, talk and undertake leisure activities with one another and receive psycho-education.

The ultimate aim of the support groups is to prevent children from developing serious problems. This aim is addressed through four intervention goals. The first goal is to improve *social support*. As mentioned earlier, due to a fear of stigmatization, many children of parents with a mental illness tend not to talk about their home situation (Hinshaw, 2014). In the support groups, children discover that they are not the only ones with a mentally ill or addicted parent. The second goal is *to reduce negative cognitions*. The parent's changeable and often-unpredictable behavior may create thoughts of confusion, helplessness, and disappointment in children. The third goal is to *improve competence by enhancing coping skills* related to problem solving, bullying and talking with others about their parent. The fourth goal is to *improve parent-child interaction*. Parents are involved with the support groups through a parent's session and a session with one's own family. Important information that is shared with children and parents focuses on mental health literacy (signs, symptoms, treatments, and medications) and the types of services available for children and their parents (Reupert & Maybery, 2011).

In a Randomized Controlled Trial (RCT) of preventive support groups for children of mentally ill and/or addicted parents Van Santvoort et al. (2014) found an improvement in terms of problem-solving scores in the intervention group one year after baseline. In addition to these family-intervention programs, peer-support programs, on-line interventions, chat programs (Drost & Schippers, 2015) and the use of e-books, online information printed books and folders have been developed (Reupert et al. 2013).

Enns et al. (2015) found in their systematic review several family-oriented mental health interventions directed at children, their care givers, or both. These programs frequently had an educational approach to teach parents strategies to help manage or prevent depression, anger, aggression, poor academic performance, and hyperactivity in their children. These programs were identified to improve child developmental outcomes such as social competence, communication skills, and problem-solving abilities by improving parenting competence, parental well-being and/or the quality of parent–child relationships.

## Support for parents by family and by professionals

All in all support and protection for children of parents with mental health problems has a long history. No such history is apparent with respect to the support of their parents in the role of father or mother. In the majority of cases, neither programs nor other structural support for patients in their role as parents is available, although in individual cases, support for the parental role might have been supplied. The focus of treatment has long been on symptoms and limitations related to their mental illness. In the following section, a sketch will be given of how recently support and programs around the parental role have been developed.

For parents with mental health problems, family relationships have positive and negative effects. Family members can be a first source of support. The relationship between the parent and his/her family is, however, not always good and supporting. In a review of Ackerson (2003a), it is described how parents express their difficulties with maintaining relationships with partners, their parents and other family members whereas these family members could fulfill a key role in times of crisis. A negative aspect of family relationships is the amount of stress that can be caused by the effort to maintain such relationships.

Professionals are not always familiar with working with clients who have children and experience child-related needs. When professionals are aware of their client's parental role, they occasionally do not know how to manage the situation and show reticence to act. Instead of coaching the parents, they occasionally choose to work on solutions such as out-of-home placement of the children (Thoburn, 2008; Knorth & Koopmans, 2012).

In their systematic review Reupert & Maybery (2011) concluded that addressing parenting issues in conjunction with parents' mental health needs was important when working with these parents. The authors also recommended numerous parent-focused services, including family therapy, parenting skills, communication skills training, accessing resources for children, and peer-support groups (White, McGrew & Salyers, 2013; Hinden, Biebel, Nicholson, Henry, & Katz-Leavy, 2006; Nicholson et al. 2001). In addition, parenting-related on-line programs have been developed. Based on the results of an RCT, Kaplan, Solomon, Salzer & Brusilovskiy (2014) concluded that mothers with a severe mental illness are interested in and capable of receiving online parenting education and support. Findings in this study demonstrate that an online parenting intervention can improve parenting and coping skills and decrease parental stress.

When making decisions about their children, most parents want to be autonomous and do not always want others' involvement that would touch the intimate contact between a parent and his or her child. It can be difficult for parents to request support. Parents are afraid that it will lead to family, friends or professionals being able to examine one's private life. The parental role is pre-eminently a role that people themselves must develop. In association with mental health problems, developing that role can be part of their recovery process.

## Recovery and parenting

The recovery movement that started at the end of the 1980s offered a new direction to improve life in cases of mental health problems (Deegan, 1987). Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental health problems (Anthony, 1993). Recovery is generally considered a personal journey rather than an outcome, one that may involve developing hope, a secure base, sense of self, supportive relationships, empowerment, social inclusion, coping skills, meaning (Repper & Perkins, 2006) and real-world personal experiences (Ashcraft, Anthony & Jaccard, 2008). Recovery is a journey of healing and transformation that enables a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential (Deegan, 1988). Recovery involves working with experts by experience, peer groups and professionals who have an attitude based on the principles of recovery. From a systematic review on this subject, it is concluded that the term 'personal recovery' gives more meaning to the concept (Slade et al. 2012) and that the term can be distinguished from 'clinical recovery', which is aimed at symptom remission and restoration of functioning**.** This study, continued in that research group by Leamy et al. (2011), identified five aspects of personal recovery: Connectedness, Hope and optimism, Identity, Meaning and purpose and Empowerment (the so called CHIME framework).

Various researchers have studied recovery in the context of parenting. Topor et al. (2006) concluded that support within the family by way of "being there" can help parents in their recovery process. One of the themes that Carpenter-Song & Nicholson (2012) found is that parenting provides a positively valued identity. Bonfils, Adams, Firmin, White, & Salyers (2014) concluded that parents with mental health problems might benefit from help to be more active and interested in information about their illnesses. In the case of psychiatric problems, parents must be supported according to their own values and without judgment to facilitate their own development. Taking the strengths and the opportunities expressed by the parents themselves as a starting point can be fundamental in recovery processes. Although all families are different and have their own unique story to tell, researchers are seeking a consensual, conceptual framework for families with mental health problems, in which the heterogeneity of families in terms of parental illness, family form and life style, culture and language are central concepts (Maybery, Reupert, Nicholson, Göpfert, Seeman 2015). With the focus on parenting in this thesis, we wanted to investigate what parenting means to people with mental health problems. How can these parents be empowered to shape their role as a parent to be an important source of affection and support so set examples for their child? By empowerment we mean "the process by which people who have been rendered powerless or marginalized develop the skills to take control of their lives and their environment" (Kosciulek, 1999). We focused on the possibilities and strengths in the parental role starting from the experiences and values of these parents themselves and

from the presumption that when people are supported to achieve their stated goals their quality of life improves (Anthony, Cohen, Farkas & Gagne, 2002).

## Psychiatric rehabilitation as a tool to support the parental role

Related to personal recovery is the concept of 'psychiatric rehabilitation'. Personal recovery is a process in which people with mental health problems themselves are in the lead. Psychiatric rehabilitation is provided by mental health professionals to help people with mental health problems to achieve their living, working, learning and socializing goals of own preference. While recovery covers all aspects of life, psychiatric rehabilitation covers only social role functioning, for instance in the role of a worker, dweller, student or parent. Psychiatric rehabilitation promotes full community integration, improved quality of life and rehabilitation for persons who have been diagnosed with any mental health condition that seriously impairs their ability to lead meaningful lives (Farkas & Anthony, 1991; Korevaar & Dröes, 2011; PRA, 2015). Psychiatric rehabilitation services are collaborative, person-directed and individualized. These services are an

## Box 1: The choose-keep-get-model

**(Farkas & Anthony, 2010)**

The cornerstone of psychiatric rehabilitation interventions is a commitment to a strong partnership between the professional and the person who is receiving support. The approach defines the process both from the frame of reference of the person supported and from the professional's point of reference (i.e., 'nothing about us without us').

The main phases in the rehabilitation process are choosing, getting and keeping a valued role.

- The choosing process is to help persons engage in determining where and in what role they want to live, learn, work or socialize, then determining a goal that 'fits'. Another element of the choosing process is providing an opportunity for a person to assess the extent to which s/he is ready to begin to make a change. Then, an overall goal is set that specifies the preferred valued role and setting, an initial and critical part of rehabilitation driving the rest of the process.
- The getting process involves intervening in the environment to help people link with opportunities that exist or to help create more opportunities to obtain the roles they want.
- Keeping valued roles is the next Component. It is based on the principle that improving skills and/or supports critical to functioning in the person's chosen role lead to success and satisfaction.

essential element of the health care and human services spectrum and focus on helping individuals develop skills and access resources needed to increase their capacity to be successful and satisfied in the living, working, learning, and social environments of their choice.

Rehabilitation has a defined set of values, techniques, program practices and relevant outcomes that have been developed over the past thirty years. Psychiatric rehabilitation like the choose-get-keep model' (developed by Farkas & Anthony, 2010 see box 1) is effective in improving housing, quality of life, psychological health (Shern et al. 2000) and social functioning (Gigantesco et al. 2006). Swildens et al. (2011) found successes in the areas of societal participation, social contacts, work and education.

Closely related to recovery and psychiatric rehabilitation is recovery-oriented care (Dröes, 2012) in which the professional recognizes and uses a patient's expertise, empowerment and network and listens to the patient's story that is told in the patient's own way, followed by the patient requested support.

In the past 15 years, the parental role has received increased attention in psychiatric rehabilitation (Nicholson et al. 2001; Ackerson, 2003a; Mowbray et al. 2001, Nicholson & Deveney, 2009). It was emphasized that rehabilitation approaches should address the parental needs of the person in recovery. Howard & Underdown (2011) conclude from a systematic review, "Although a significant proportion of parents with severe mental illness do lose custody, many can successfully parent if adequate support is available and needs are assessed and managed by a multi-disciplinary team". The effects of parental mental illness and, particularly, maternal depression, on children, have been conceptualized as two-generational or multigenerational, with a call for effective treatment of parents' mental illnesses to promote successful parenting and improve outcomes for children (Nicholson & Deveney, 2009).

Specific parenting programs based on psychiatric rehabilitation were not available before the 1990's in the US and until 2005 not in The Netherlands. Nurses and social workers of the adult psychiatry department of a mental health organization in Groningen, the Netherlands, expressed their need for developing competencies and skills to support the parenting of their patients. To fill that need, an intervention was developed. That intervention is described in the following.

## Parenting with Success and Satisfaction (PARSS), a new approach for parenting

The program, Parenting with Success and Satisfaction (PARSS), is an intervention based on psychiatric rehabilitation to support parents through professionals (Parenting with Success and Satisfaction, Van der Ende, Venderink & Van Busschbach, 2010 see also website www.ouderschap-psychiatrie.nl). The aim of PARSS is to support individuals in developing skills and accessing the resources necessary to be successful and satisfied in their parental role and in their family life. This approach, inspired by the psychiatric

rehabilitation approach, comprises a method that helps parents to explore, choose and maintain their parental goals. The intervention explicitly targets parental attitude and behavior rather than diagnostic-specific characteristics as a useful strategy in developing interventions for parents and their families. Parents with mental health problems are eligible for this program.

After tryouts with PARSS, a pilot study was performed to evaluate the experiences with and effects of this intervention. This pilot study was intended not only to explore the benefits that can be gained from participation in PARSS but also to identify adequate procedures and measures for implementing and evaluating an intervention of this type. In Chapter 5 more information is given about this program and the pilot study and a more extended description of the program is given in appendix 2.

## Four studies

The chapters of this thesis describe current knowledge about parents with mental health problems, their personal recovery strategies, and the development and evaluation of a program for supported parenting. Four studies, one with a qualitative design and three with quantitative designs, have been executed to contribute these themes.

*Aims of these studies*

A. The purpose of the first study was to assess the scope of the group of parents with severe mental illness. The question was how many people between 18 and 65 with SMI in the Netherlands had one or more children in 2009. This figure is relevant because it supports the need for adequate interventions for this group.
B. The aim of the second, exploratory study was to gain in-depth knowledge of the challenges, strengths and strategies of people with mental health problems who have parenting goals and tasks, and of the meaning of parenting in their recovery processes. The main research question addressed the strategies that mothers and fathers living with mental health problems use to parent successfully and with satisfaction.
C. The third study aimed to characterize differences between mental health organizations and general hospitals in providing support to parents. In an explorative study with a cross-sectional design, information on supported parenting was collected through an internet questionnaire directed at professionals in both mental health organizations and general hospitals.
D. The aim of the fourth study was to explore the initial experiences with and effect of Parenting with Success and Satisfaction (PARSS), the psychiatric rehabilitation- and recovery-based, guided self-help intervention, for parents with severe mental illnesses.

## Outline of this thesis

In **Chapter 2** epidemiological data of parents with mental health problems are provided (study A). Because not every organization registers the children of people with mental health problems and no direct surveys are executed, only estimations based on surveys and national population data on mental illness are used to estimate the number of parents with mental illness. Three sources were used:

- CBS (Central Bureau of Statistics) for the year 2009 (CBS Statline, 2010) to determine the size of the total group of parents
- Population research NEMESIS-2 (De Graaf, Ten Have, Dorsselaer, 2010) to determine how many people had psychiatric problems matching a psychiatric diagnosis within the criteria of the DSM-IV over the past year
- The vision statement of Mental Health Organizations the Netherlands (MHO) "To Recovery and Equal Citizenship" to determine how many people with SMI can be found within the total group of people with psychiatric problems.

C**hapter 3** is the report of the qualitative study (B) with 27 parents with mental health problems. The aim was to gain insight into the parenting experiences of women and men living with mental health problems and into the strategies that they develop to be successful in their parental role. Taking the strength and the opportunities as formulated by parents themselves as a starting point is new. In the study on strategies of parents, experiences of 19 mothers and 8 fathers with SMI were explored with in-depth interviews. Data were content analyzed using qualitative methods and computer-based data management software.

**Chapter 4** describes study (C) on the extent to which different professionals in general and mental health care provide support for parenting. This comparison provides a snapshot of the availability of supported parenting and identifies organizations that can serve as an example for other organizations. The amount and content of support that is provided by professionals in mental health institutions and general hospitals is the central question in this chapter. To answer this question, an internet survey is used and a cross-sectional design with three groups of respondents (total 128) was chosen. The first group comprised professionals in two mental health organizations who had previously received the PARSS training. The second group of respondents consisted of professionals from two nearby mental health organizations in which no such training had been offered. The third group was composed of health professionals of long stay departments at three general hospitals.

In **Chapter 5,** the program "Parenting with Success and Satisfaction (PARSS)" is evaluated by a pilot study (D) with an experimental and a control group. During one year, a trained group of professionals and the parents they support have been followed.

Changes in the intervention group (11 participants) were compared with changes in a control group (15 participants) in a non-equivalent control group design. Outcome measures included parenting satisfaction reported by parents; parenting success reported by mental health practitioners and family members; empowerment as reported by parents, practitioners and family members; and parents' reported quality of life. Additional process data were obtained on relationship with practitioner, quality of contact, satisfaction with the intervention and fidelity.

**Chapter 6** constitutes the general discussion of this thesis. The contribution to epidemiological knowledge about parents with mental health problems, to knowledge about strategies for the parental role and to the possibilities and needs for support of parents themselves are weighed. Additionally, an evaluation of the development of research instruments for programs of parenting by people with mental health problems is executed.

# CHAPTER 2

## PARENTS WITH SEVERE MENTAL ILLNESS. EPIDEMIOLOGICAL DATA.

**This chapter is based on a translation from Dutch of the article:**
Van der Ende, P. C., Van Busschbach, J. T., Wiersma, D., & Korevaar, E. L. (2011). Ouders met ernstige psychische aandoeningen. Epidemiologische gegevens. [Parents with severe mental illness. Epidemiological data]. *Tijdschrift voor Psychiatrie*, *53*, 851– 856.

## Summary

**Background:** It is becoming increasingly clear that people with severe mental illness (SMI) are in need of support with parenting. So far, however, little is known about how many persons fall into this category.

**Aim:** To estimate how many SMI patients aged 18 to 65 are parents with children and how many need help with parenting.

**Method:** We based our estimate on epidemiological studies and on official records and data relating to SMI patients for the year 2009.

**Results:** We estimated that 48% of patients with SMI had children. The total number of such patients for the year 2009 was 68,000; this figure represented 0.9% of the Dutch population in the 18-65 age-group.

**Conclusion:** Health professionals and carers need to be alerted to the fact that almost 50%of the patients with SMI require possibly help in fulfilling their parental role. Potential problems in the parent-child relationship need to be registered in greater details so that more adequate care can be provided both at individual level and national level.

## Introduction

> **Carla is a single mom with borderline problems who has been admitted to a psychiatric hospital and is currently reobtaining parenting responsibility over her two children from their grandma.**

> **Jan is a man with a long-term depression trying to add content to the visiting arrangement with his daughter.**

> **Karin is a mother of three children who suffers from psychotic episodes and during such episodes has her children sleep over at their friends' parents.**

Carla, Jan and Karin stand as examples of people with psychiatric problems who fulfill a parental role. It is known that people with mental illness have or conceive children but the number of these people in the Netherlands is virtually unknown. Parenting in combination with psychiatric problems is poorly registered.

One can assume that especially because of health care becoming more of a social matter, the number of parents among people with psychiatric problems is increasing.

The purpose of the study here presented is to assess the scope of the group of parents with severe mental illness. The question is: how many people between 18 and 65 with SMI had one or more child/ren in 2009? This figure is relevant because it supports the development of an adequate care supply for this group.

## Methods

*Definition of the group of participants:*

To identify parents with SMI within the entire population of patients suffering from psychiatric problems, we adopted the currently used definition of SMI. The SMI group includes patients with severe mental health disorders, which have caused the patients to suffer from functional disabilities for a long time (i.e., function poorly or in a mediocre manner) and aside from such disabilities, experience severe and complex problems in different life domains. Most of these patients often suffer from psychotic episodes, severe bipolar disorders and other severe Axis I and Axis II disorders. Frequently, these patients are being treated or require treatment for an (expected) duration of at least two years (Mulder et al., 2010, see also Ruggeri, 2000, Kroon et al.). As distinct long-term care programs are designed to address the needs for care of this group, the group can also be defined as patients who receive treatment from these facilities. (Mulder et al., 2010).

*Figures from (mental health) care*

An indication of the number of parents with SMI was found in the Utopia study in which 21 organizations for supported housing and supported independent living (in Dutch: Regionale Instelling voor Beschermd Wonen, RIBW) participated (De Heer-Wunderink et al., 2007). As a part of this research sociodemographic data of all patients receiving long term support in their own homes or in homes provided by the organization were presented. It appeared that on January 1st of 2006 26 % of this group had children of their own (N = 3521, age 16 to 101).

*Figures from population research*

In the Utopia research, however not a representative sample of all people with SMI is found. In the following research an attempt was made to determine how many parents from the total group of people with children, also battle with severe mental disorders. For this analysis three sources were used:

- Data from the Central Bureau of Statistics (CBS) over the year 2009 (CBS Statline, 2010) to determine the size of the total group of parents.
- Data from the population study NEMESIS-2 (De Graaf et al., 2010) to determine how many people had psychiatric problems matching a psychiatric diagnosis within the criteria of the DSM-IV over the past year. Available are data of a sample survey of 6646 respondents between 18 and 65, with whom the CIDI (Composition International Diagnostic Interview, WHO, 1990) has been administered. Although NEMESIS-2 offers a representative image of the entire Dutch population, an underrepresented population segment includes people receiving treatment in hospitals or other forms of inpatient care because no interviews were conducted in these facilities. As non-response can also be expected to be high when people suffer

from disabilities in (social) functioning, NEMESIS data do not constitute a reliable source of information on parents with severe mental illness.

In a vision statement, called To Recovery and Equal Citizenship (2009) from the Dutch National Mental Health Organization (In Dutch: GGZ Nederland) figures can be found on the percentage of people with SMI within the total group of people with psychiatric problems. In this statement data on patients in mental health care are derived from the "Care Information" system of the Dutch Ministry of Health, Welfare and Sport over 2006 and complemented with an estimation of the number of people who are not in care with the formal mental health institutions but are known to have severe mental disorders from reports of general practitioners, police or staff of facilities for the homeless (about one third of the total SMI population, Van Busschbach et al., 2004).

## Results

Our research takes as point of departure the number of people with children out of the population as a whole. By combining figures of CBS with results of NEMESIS-2 we could assess the number of parents who suffer from mental illness in one year. Combining these data with those of the number of people with SMI among the total sum of people with psychiatric problems produced an eventual estimation of the number of people with SMI.

In the following three tables the number of parents out of the population as a whole, the percentage of parents with mental illness out of all people with severe mental illness and finally the number of parents with severe mental illness have been calculated successively.

In table 1 CBS data of the population with and without children in numbers and percentages are rendered. In 2009 54, 9 % of people between 18 and 65 with partners had children. Out of the people without a partner in this age category 5.9 % was a dad or mom (CBS-statline, 2010).

**Table 1: CBS data population between 18 and 65 years old in 2009 without and with children**

| | Population (CBS, 2009) 18 – 65 years[1] | |
|---|---|---|
| | N | % |
| All | 7.312.718 | 100% |
| Without children | 2.865.540 | 39.2% |
| With children | 4.447.178 | 60.8% |
| Among which: | | |
| • parents with partner | 4.014.787 | 54.9% |
| • single parents | 432.391 | 5.9% |

1) Children living at home and other members of the household not counted

In NEMESIS-2 (figure 2) it was found that in one year 18% of people between 18 and 65 suffered from psychiatric problems. In NEMESIS-2 the family situation is inquired after directly and so it is known that among parents with a partner 13.2 % has mental disorders and among those without a partner the percentage is 23.9 (%) (De Graaf et al., 2010).

**Table 2: People with mental disorders between 18 – 65 years, who have children based on NEMESIS-2**

| Mental disorders | Year prevalence (NEMESIS-2, 2010, 18 - 65) | |
|---|---|---|
| | % of population | N |
| Total mental disorders | 18% | 1.316.289[1] |
| Parents with partner | 13.2% | 529.952[2] |
| Single parents | 23.9% | 103.341[3] |
| Total with children | | 633.293 |

1) NOTE this is calculated from population between 18 and 65 (7.312.718)

2) This is calculated from the number of parents out of population in this category 13.2 % of 4.014.787 (from figure 1) = 529.952

3) idem, 23.9 % of 432.391 = 103.341

Calculated into absolute amounts based on population figures of the year 2009 it can be estimated that in that year 633.293 parents with psychiatric problems. This is 48.1 % (633.293/1.316.289) of the sum of people with psychiatric problems.

However, in our study the focus is not so much on the larger group of people with psychiatric problems but the group with severe psychiatric problems.

Table 3 shows a figure of 140.464 people (18 and above) with severe mental illnesses, stemming from the vision statement of GGz-Nederland: *To Recovery and Equal Citizenship* (2009).

**Table 3: People with Severe Mental Illnesses with children**

| | Year prevalence, SMI (GGz Nederland, 2009) 18 – 65y. | |
|---|---|---|
| | N | % of population |
| Total severe mental disorders | 140.4641 | 1.9% |
| Parents with SMI | 67.5632 | 0.9% |

1) The original figure from this statement was 160.000 and contained people above 65 as well. This is calculated into the group between 18 and 65

2) Parents with SMI = the percentage of parents with mental disorders in general, applied to people with SMI = 48.1 % of 140.464 = 67.563

With the help of the data above we can, moreover, assess the year prevalence for people with severe mental illnesses who have children. Starting point is the percentage found in the NEMESIS-2 study: out of people with psychiatric problems 48.1 % is a parent. If we assume this percentage goes for people with SMI as well 48.1 % of all people with SMI is a parent. The absolute figure amounts to 67.563 (rounded off to 68.000). Using these stats for the estimation of the percentage of parents with SMI out of the whole population between 18 and 65, this boils down to (67.563/7.312. 718 =) 0.9 %.

## Discussion

*Estimations, not registration data*

In this paper we have made an estimation of the number of parents with SMI in the year 2009 in the Netherlands. This was conducted utilizing data from a study on characteristics of those in care of organizations for supported housing and by extrapolation of data from population research. The percentage of 26 % which was determined from the population in supported housing is lower than the estimated percentage of 48 % on grounds of population research. Probably the group with the most severe problems can be encountered within these supported housing facilities. Patients in care at community mental health centers possibly have less severe problems and a larger percentage has child/ren. The estimate of the percentage of parents within the total group of patients with mental illnesses in general is used to make the estimate of the percentage of parents in the group with SMI. The question arises whether the implicit assumption that both percentages are equally large, is correct.

For an epidemiological study, not only current problems but also specific diagnoses and assessments of deficits in functioning should be used to obtain a more accurate estimate of the SMI population. Furthermore, population studies such as NEMESIS-2 underrepresent the proportion of individuals with SMI. Hence, the percentage of patients with SMI and the number of such patients with children might be higher than was reported in this study. Only registration of parenting responsibilities can offer more clarity. In questions posed in the Dutch parliament (Kamerstuk, 2009, CZ/CGGZ-2927603) attention is asked for the lack of these data in registrations. Within the institutions there are however possibilities for the registration of children and of problems around parenting.

If axis-IV of the DSM-IV-TR (APA, 2001) were to be consequently applied, the code: *V61.20 Parent-child relation problem* would help to gain a better understanding of the problem at hand. In this code a troubled interaction between parent and child, dysfunctionality of the individual or the family, or symptoms whether with parent or child are taken into account. Furthermore one can also indicate that there are no problems in the parent-child relationship.

*Supervision accompanying parenting*

Parenting is a challenge for anyone; the development of children demands that parents adapt their behavior to the ever changing needs of the child. Parenting can be even more difficult for people who have less capacity because of severe mental illnesses. There is a chance that they will be burdened by their children's demands. The goal that lies behind determining the size of the group of parents therefore was the question as to the necessity of deploying interventions. The numbers indicate that we are dealing with an extensive target group that is possibly seeking support with parenting. Furthermore it is important to emphasize that an adequate supply of (mental health) care would prove helpful not only to the patient but also to the children involved. With extra support situations of disruption can be prevented and parents can continue to exercise their parenting in one form or another. Intensive cooperation with child- and youth care institutions could help accomplish this goal. Within mental health care and supported housing different methods to help parents exist such as family counseling, video home training and Triple-P. For supervision in a psychiatric setting there is a method based on the Individual Rehabilitation Approach (IRB, Van der Ende et al., 2010), a method for supported parenting chiefly aimed at parents with SMI but possibly helpful to parents with a mild or medium mental dysfunction as well. The rehabilitation approach and alongside that, the motion towards the recovery of the parent him/herself offer space for a positive approach aiming at what exactly one can and wants to achieve as a parent.

# CHAPTER 3

## STRATEGIES FOR PARENTING BY MOTHERS AND FATHERS WITH A MENTAL ILLNESS[2]

**This chapter is based on the article:**

Van der Ende, P.C., Van Busschbach, J.T., Nicholson, J., Korevaar, E.L. & Van Weeghel, J. (2015). Strategies for parenting by mothers and fathers with a mental illness. *Journal of Psychiatric and Mental Health Nursing* 2016 23, 86–97 doi: 10.1111/jpm.12283.

2 In this chapter British- English language will be used, because it is based on the publication in a UK journal.

## Abstract

**Introduction:** Understanding of the problems of parents with mental illness is growing. Gaining insight into strategies for parenting, while taking the opportunities formulated by these parents themselves as a starting point is fairly new.

**Question**: What are the strategies of parents with a mental illness to be successful?

**Method:** Experiences of 19 mothers and eight fathers with a mental illness were explored with in-depth interviews. Data were content analysed, using qualitative methods.

**Results:** Next to feelings of inadequacy, interviewees also describe how children enrich and structure their lives and are not only a burden but serve as distraction from problems. Developing activities that interest both child and parent provides avenues for emerging strength. Mental illness constrains fathers, but also gives opportunities to develop a meaningful relation with their children.

**Discussion:** Strategies like being fully dedicated to the parental role, finding a balance between attention for one's own life and parenting and finding adequate sources of support are found to be fundamental for recovery in the parent role.

**Implications for practice**: Peer groups can be of valuable help and mental health workers can support parents to set self-chosen parenting related goals.

## Accessible summary

*What is known on the subject?*

- The combination of coping with their mental health problems and caring for children makes parents vulnerable.
- Family-centred practice can help to maintain and strengthen important family relationships, and to identify and enhance the strengths of a parent with a mental illness, all contributing to the recovery of the person with the mental illness.

*What this paper adds to the existing knowledge?*

- Taking the strength and the opportunities formulated by parents themselves as a starting point is fairly new.
- Parents with severe mental illness find strength for parenting in several ways. They feel responsible, and this helps them to stay alert while parenting, whereas parenthood also offers a basis for social participation through school contacts and the child's friendships.
- Dedication to the parent role provides a focus; parents develop strengths and skills as they find a balance between attending to their own lives and caring for their children; and parenting prompts them to find adequate sources of social support.
- In this study these strategies were found to be the fundamentals of recovery related to parenting.

*What are the implications for practice?*

- Nurses can support and coach patients who are identified as parents and self-chosen parenting related goals are set and addressed.
- A family-focused approach by nurses can be used to prevent problems for children and their families, identify their strengths as well as vulnerabilities, and address the challenges to build resilience.

## Introduction

During an episode of mental health problems, people may leave or lose social roles, such as that of employee or student, for a short or longer period (Hunt & Stein 2012). Functioning in the parenting role can also be disrupted or restricted when mental health problems intensify or when a parent is admitted to a psychiatric hospital. There are many who face the challenge of combining (severe) mental illness (SMI) with parenting tasks. In the United States, about two-thirds of people meeting the criteria for SMI and living in the community had children (Nicholson et al. 2004). In The Netherlands, it is estimated that 48% of the people with SMI were parents of children younger than 18 years of age (Van der Ende et al. 2011).

In general, parenting varies from so-called 'good enough parenting' to 'problematic parenting' (Eckshtain et al. 2009).

The combination of coping with mental health conditions and caring for children makes parents more vulnerable to stress and challenges. Seeman (2012) found that in the United Kingdom, almost 70% of mothers with the diagnosis of schizophrenia lost custody of their children. Dipple et al. (2002) found 68% of parents with mental illness were separated from their children for at least 1 year. In another study in the United States, mothers with serious mental illness were almost three times as likely to have involvement with the child welfare system or to have had children in out-of-home placement (Park et al. 2006). If children stay in the family, parents may be confronted with prejudices and discrimination, given the stigma individuals with mental illness who are parents often face. Jeffery et al. (2013) reported 23% of individuals receiving community- based psychiatric services felt discriminated against for starting a family and 28% in their role as a parent.

Essential social support, like providing information about making the best of the parental role in this situation and offering opportunities for conversation about feelings and possibilities, is not always available; fear of stigmatisation often renders the topic off-limits and leads to secrecy and concealment (Hinshaw 2005).

To date, several studies have addressed the need for support for parents with SMI (Nicholson & Deveney 2009; Howard & Underdown 2011; Reupert & Maybery 2011). Family-centred practice can help maintain and strengthen important family relationships, and identify and enhance the strengths of a parent with a mental illness, all contributing to the recovery of the person with the mental illness (Goodyear et al. 2015). The way these parents develop in and value their role can also be seen in the context of a recovery process (Bonfils et al. 2014). From this perspective it is important to understand more about the meaning of parenting and the strategies parents can develop to deal with the challenges and vulnerabilities that a mental illness may convey. By giving parents the opportunity to tell their own stories, with an emphasis on how they manage to parent, insight can be gained that can be helpful in creating supportive arrangements for others. It is important to understand differences in how both mothers and fathers value and

shape their role of parents. Mothers may have no choice but to care for their children even when they are ill (Nicholson et al. 1999), whereas only one of four men with severe mental illness is actually parenting (Luciano et al. 2014).

A number of qualitative and quantitative studies on parents living with a mental illness have been conducted. Topics in selected studies include the prevalence of parents with mental illness (Nicholson et al. 2004), assessment of their needs (Howard & Underdown, 2011), and the development and evaluation of programmes (White et al. 2013). However, not much is known about the way these mothers and fathers come to grips with challenges in their parental role or about the meaning of parenting in their recovery processes. The strategies they use can give an input to the recovery of others. To learn more about these strategies and processes, a qualitative, exploratory approach is appropriate.

Because fathers with a mental illness are frequently a minority or totally absent in studies on parenting, there is an additional need to understand how they see their role and, for those who actively parent, what ways of coping they have found. Reupert & Maybery (2009) investigated fathers' needs and also the relationship between paternal mental illness and children's development but did not focus on their strategies for dealing with fatherhood.

*Aim and research question*

The aim of this exploratory study was to gain in-depth knowledge into the challenges, strengths and strategies of people with mental illnesses who have parenting goals and tasks, and the meaning of parenting in their recovery processes. The main research question was: What are the strategies of mothers and fathers living with a mental illness to parent successfully and with satisfaction?

## Method

*Personal characteristics and relationships with participants*

The two interviewers (female) and the researcher (male) were trained in research and were interested in the subject of recovery and supported parenting. Only the interviewer and the participant were present during the interview. Because of purposive sampling, the contact persons invited several people.

*Theoretical framework*

For this exploratory study, qualitative methods were used. This approach was appropriate given that our aim was to obtain rich narrative descriptions of the parenting experiences of women and men living with mental illness in the context of their everyday lives (Holloway 1997; Patton 2005). The open-ended nature of the interviews gave participants the opportunity to talk in a non-restricted way about their own experiences, challenges, strengths and opportunities. An iterative method was used, in which gathering data and

drawing inductive conclusions were implemented in a circular design (Miles & Huberman 1994; Maxwell 2004). Reflecting on the data from the interviews, new questions were asked and, in a process of purposive sampling, new types of participants were invited for interviews, to explore the issues more fully. Also a narrative approach (Miles & Huberman 1994) was used with extra attention to patterns of inter-connection in the data that differed from what might have been expected, the so-called 'following up surprises' that have the potential to reveal patterns, which might be very informative.

*Participant selection*

The sampling for this study was purposive. Participants were recruited who met the study criteria of having a psychiatric diagnosis while actively parenting at least one child younger than 21 years of age in the past year. In addition, participants were invited to participate who were perceived as able to express their feelings about parenting verbally. Participants were recruited through three sources. In the first place, teachers of the Expert by Experience education programme at a university for applied sciences asked adult students with children to participate in the study. The Expert by Experience programme is a 2- year associate bachelors' degree programme for people who are, or were, consumers of mental health services. Second, providers from mental health organizations in our professional network invited patients who had children. A third source was parents outside of our network, several of whom volunteered themselves after participating in a workshop about supported parenting.

After the first 10 interviews, the collected data were reviewed and analysed by the first author: (1) to ensure the interviews were meeting the aims of the study; and (2) to establish the types of additional participants who were needed to provide a broad perspective on the parenting experience, to inform further purposive sampling (Patton 1990). This led to the conclusion that it was necessary to recruit more male participants and more people with substance abuse issues. Among the first 10 participants, only one person with substance abuse issues emerged. Given that parents with co-occurring mental illness and substance abuse issues might have specific challenges, strength and opportunities, the decision was made to engage more participants to meet these criteria. All participants gave written informed consent. Full review of study procedures was waived by the Dutch Medical Review and Ethics Committee as the risk to the participants posed by the study were thought to be minimal. No intrusive questions were asked.

For this portion of the thesis, we did not differentiate between a mental illness and a severe mental illness when recruiting participants, but focused on parents interested in speaking about how they had coped with the challenges of parenthood in the presence of mental health problems. Consequently, verbally competent people, who had mostly overcome their problems, were overrepresented in our sample. Table 1 clarifies that based upon the diagnosis and the duration of the mental health problems, most

participants nonetheless belonged to the group of people with severe mental illness, and all participants had previously received long-term care.

A gift amount of 25 euros was given to each participant. This is an amount common in research in The Netherlands as return for participation in interviews of 1–2 h. Since participants were directly invited for these interviews, no response bias was expected from this gift. Since all participants had an income from salary or health benefit and the gift was not extreme (did not exceed a 2 h salary) we do not think it can be seen as coercive.

*Setting*

The interviews were conducted at locations that the parents preferred, at a time convenient for them. Two interviews took place at a parent's work site, three in a psychiatric hospital, and the rest of the parents were interviewed at home.

The 27 participants in this study were between 19 and 59 years old. Their youngest children were between 6 months and 18 years of age (see Table 1). The sample included 19 mothers and 8 fathers, with more than half of them living with a partner. Half of both the mothers and the fathers were working in a voluntary or paid job. Mood disorders, psychotic disorders and borderline personality disorders were the primary psychiatric diagnoses in this group of participants. Mental health problems tended to be of long duration, with a range from 8 months to 50 years. Seventy-eight percent of the parents had mental health problems before their youngest child was born. Twenty-five parents lived with their children at the time of the interview. The children of two respondents lived with foster families.

**Table 1. Demographic data of the study participants (N=27)**

| Description | Mothers (n=19) | Fathers (n=8) |
|---|---|---|
| Age | | |
| Min. - max. | 19 – 54y | 30 – 52y |
| • 19 - 30y | 2 | 1 |
| • 31 - 40y | 2 | 4 |
| • 41 - 50y | 12 | 2 |
| • 51+ | 3 | 1 |
| Marital Status | | |
| • Married/in a relationship | 8 | 6 |
| • Divorced/widow | 4 | 1 |
| • Unmarried | 7 | 1 |
| Living arrangement | | |
| • Independent | 16 | 5 |
| • Sheltered/supported | 3 | 3 |
| Highest education | | |
| • University/college | 2 | - |
| • Middle school/junior high | 7 | 3 |
| • Elementary school/basic | 10 | 5 |
| • education | | |
| Employment or other regular daytime activities | 9 | 5 |
| Number of children | | |
| • 1-2 | 13 | 5 |
| • 3-6 | 6 | 3 |
| Age youngest child | | |
| Min - max | 1-18y | 0.6-11y |
| • 0 - 5 y. | 6 | 4 |
| • 6 -11 y. | 6 | 3 |
| • 12-18 | 7 | 1 |
| Psychiatric diagnosis | | |
| • Mood disorder | 5 | 4 |
| • Anxiety disorder/PTSS | 1 | - |
| • Psychotic disorder | 5 | 1 |
| • Addiction | 2 | - |
| • Personality disorder | 5 | 2 |
| • ADHD | 1 | 1 |
| Duration problems | | |
| Min-max | 1- 50y | 0.7 - 15y |
| Shorter than 10 years | 3 | 5 |
| • 11-20 | 9 | 3 |
| • 21 years and longer | 7 | - |
| Total | 19 | 8 |

*Data collection*

An in-depth interview guide was used to elicit data about parents' experiences. The guide comprised open-ended questions such as: 'What does parenting mean to you?' 'What are the effects of your mental illness on parenting?' and 'What strategies do you use to overcome your disabilities?' The interviews were audio recorded and typed out verbatim. Two participants checked their own typed out interviews (member check); both evaluated the reports as complete. The interviews lasted about 1½ h. Because of purposive sampling, the contact persons invited several people. Refusal to participate was not recorded or evaluated. Only the interviewer and the participant were present during the interviews.

*Data analysis*

The first author conducted a careful review process with interview transcripts, searching for new concepts and associations in this area. Themes emerged and codes were assigned. Recurrent issues were identified by a thematic analysis of the data (Miles & Huberman 1994). Using Atlas-TI (a qualitative data analysing software program, Muhr 2004), the first author began axial coding. After this process selective coding is used to derive themes from the data (Miles & Huberman 1994). A total of 21 salient themes emerged. Three interviews were selected at random and checked by an independent researcher who gave additional viewpoints with regard to the coding process. Data from mothers and fathers were reviewed and analysed separately, and compared across sources. The themes that emerged regarding the impact of mental illness on parenting distinguished mothers from fathers. Consequently distinct codes were developed. Themes regarding successful parenting strategies converged across data sources, with mothers and fathers both providing evidence of common themes.

*Reporting*

In the Results section the major strategies of parents with psychiatric disabilities are presented. Some findings around the main strategies are consistent across participants and in previous research, but also new and unique information is found. The diversity of cases is described as are the individual themes. Quotations are reported as provided by participants, and identified by participant number.

## Results

First, the results of interviews with mothers are described, starting with their perceptions of the negative effects of mental illness on parenting and then followed by their reports of the positive aspects of having children. Next, the findings pertaining to the parenting experiences of the fathers are presented. We conclude with the overall parenting strategies that emerged in these interviews.

## Effects of mental illness on parenting – mothers

All the mothers said that their mental illness caused parenting problems, on top of the challenges every parent experiences with raising children. Lack of structure and fewer social contacts, and limited energy or 'lust for life' negatively influenced their resources and time for sharing leisure activities with children and setting limits or boundaries. Besides the benefits and the problems that all people have when raising children, parents with a mental illness have an extra challenge. On the one hand, having children puts pressure on the parents, while on the other hand, the children contribute to a sense of regular life.

*Negative effects of mental illness*

*Feelings of inadequacy.* Mothers expressed feelings of inadequacy regarding their ability to demonstrate empathy, set limits and keep boundaries, structure daily life around a child's needs, and in organising and coaching children's activities as they felt a parent should.

A few mothers expressed the concern that they had failed to show their children enough empathy and understanding, which they felt was essential in the contacts with their child. A single mother with a 15-year-old daughter explained:

> *She [her daughter] felt like she was living on an island. She missed the support she needed from me, during my depression [F1].*

Mothers reported it is often difficult to handle the combination of one's own vulnerability with paying attention to the children and other obligations like housekeeping. A married mother with two children age 6 and 10 years old described:

> *After the last admissions to the hospital, I noticed that I am no longer the person who I was and that I will not be it again. I experience that it is difficult for me to do the housekeeping, to care good enough for my children; I know I have my limitations [F2].*

Some mothers felt themselves inadequate parents directly after giving birth to a baby, when they were confronted with their confusion about the big change in their families or, in some cases, by a traumatic birth. A married mother with two children ages 5 and 7 said:

> *When my first son was 1 year old, I was suicidal. I felt bad as a parent. I could not fulfil the mother role [F3].*

This inadequacy was sometimes also confirmed or independently expressed by the organisations or services that are supposed to offer support. For example a mother living with her 12-year-old child felt suppressed:

> *Before my daughter was born I went to therapy and this information was passed on to Child and Youth Care. It [the information] followed its own course. Instead of being supportive, they kept me under strict control, based on the psychiatric diagnosis in my file [F4].*

Two interviewed parents found themselves in complicated situations due to their mental illness and lost their parental status. This not only meant losing legal parental power, but also the loss of contact with the child.

*Experience of transference of problems to their children*

Several others expressed that they were afraid that their children would inherit their problems. A single mother with a son of 16 years of age said:

> *I'm really afraid that my child will go that way. He had two parents who were addicted. That will be in the genes, I'm afraid [F5].*

Some of these parents clearly expressed the need for information and support in this matter. A divorced mother with a 3-year-old son explained:

> *It would be nice if nurses talked about the transference of psychiatric problems to the children. They should make it clear that we have to deal with it . . . although it is hard to do it [F6].*

*Experience of positive aspects of having children*

*Positive stimulus to parents' life.* The birth of a child gave a positive stimulus to these mothers' lives, providing new substance to their life and a source of joy. A single mother with a 2-year-old child:

> *Motherhood gives me a lot of satisfaction and yes, since I am a mother, I have stood firmly on my feet. It has changed me a lot. I have to take responsibility that already starts after waking up. You have to be there all day; you cannot leave your child [F7].*

The burden of the parenting tasks is concrete during the first years of the child's life. For a married woman caring for a 2-year-old child the parental role meant:

> *(……) you as a mother have the lead direction, you wash them, you put on their clothes, and you feed the child [F8].*

While for an older child more emotional problems may arise. A single mother with two children ages 5 and 7 said:

> *My son gets older and now the issue is the bullying at school. I am worried about that. It is a new responsibility to me [F3].*

Issues like these, for older children, pose more emotional or social challenges, compared to when children are younger.

*Structure to life.* Having children can give structure to life. Another married mother with two children of 6 and 10 years old explained:

> *Our children helped us, because they forced us to structure our lives: rising in the morning, making breakfast, taking children to school, getting them from school, lunch … [F2].*

Due to mental health problems, the rhythm of life of these parents was disrupted but, due to the responsibility of caring for their children, a new rhythm and structure was developed.

### Effects of mental illness on parenting – fathers

In our sample eight fathers were interviewed. The amount of time they spend with their children varied from living with them full-time to visiting on weekends and holidays.

*Fathers at a distance*

Three fathers had contact with their children about once every fortnight. They fulfilled their fathering role albeit only for short periods. This limited their ability to engage in a more personal way with their children and, potentially, to overcome the stigma of being a father with mental health problems. For example a father who was divorced with an 8-year-old child had delusions and lived in sheltered housing:

> *It is like they [ex-wife and her family] see me as having a contagious disease. When I drop a cup it is not just that I do this, no it is because I have a mental illness [M9].*

It seemed that he could not do anything right in the eyes of his ex-wife. Still he fought against this, and wanted to be accepted. Another father with children of 7 and 9, married for the second time, mentioned needing support in parenting once in a while. In his case this support was provided by his second wife. Even with this support, he felt he was not taken seriously by professionals because of his mental illness:

> *Well my oldest daughter was here once when we discovered bruises, when she came from my ex-wife. We mentioned this to the AMK [child maltreatment reporting service], but they did not do anything with it. They listened to us, but did not take us seriously [M10].*

These professional helpers considered him as a questionable person, not able to have sound judgment in delicate matters such as child maltreatment.

*Empowerment, also for fathers in the background*

Four of the interviewed fathers were in the role of being 'the second parent', with the mother occupying 'first place'. The mothers, or in one case the foster family, did most of the childrearing, while the fathers had additional contact with their children. A 32-year-old man who became a father 7 weeks before the interview provided an example of how hard it was to establish a close relationship with his child. He was in a relationship, although not living together with the mother, and saw his child only a few times:

> *Glad to be a father. Because her mother breastfeeds the baby there is not much to do for a father [M11].*

He tried to be as close to his child as he could to create a bond with her. When a person feels he is improving in his role of the father, this can increase feelings of empowerment.

Developing more of a father role can be a part of one's recovery process. This was expressed by a father living with a partner and children of ages 10 and 11:

> *I learn how to regain the trust of my children. Doing nice things with them, asking them about school, being interested, and knowing when my child has to give a talk at school. Regaining my parental role is one of my key points in this clinic [M12].*

*'Role' change with the mother*

In our sample there was one father (of two children of 3 and 6 years) who had full child care responsibility, staying at home while his wife had a full-time job. He expressed the challenge conveyed by his mental illness:

> *(Earlier on) the children walked over me; I could not keep standing because of the burden of my depression [M13].*

After treatment by a psychologist he came to the insight:

> *It is like what stewardesses explain about how to handle in the case of an airplane crash: first put your oxygen mask on your own face, so next you can help your child [M13].*

This father first wanted to have control over his own life, by taking advantage of professional treatment and 'finding' himself, before he was able to be available to his children. After this insight he managed to do the housekeeping and care for the children and reflected on the positive effect this had on him.

## Strategies for successful parenting

The mothers and fathers we interviewed developed specific strategies for parenting. In these paragraphs the results are summarized under several headings. Since broad concepts of strategies are described, no distinction is made between mothers and fathers. According to the results of the interviews, their strategies are based on dedication to the parental role, finding a good balance between having children and their own activities, recovery in the context of parenting, and requesting support.

*Full dedication to the parental role*

One of the effective strategies mentioned by participants was making a plan for doing parenting activities during a week, coached by a nurse.

Another strategy suggested by parents is facilitating contact with children through shared activities and searching for joint interests. From this, it follows that an activity needs to be chosen that fits the child's age and that also gives pleasure to the parent.

Being together as a family and being a good role model is seen as important goals of the parental role. A married father with children of 1, 5 and 8 years old described how he intentionally used this strategy:

> *Getting up in the morning, together as a family, eating together again, doing family things together, yes, that is coming back [M14].*

Loss of dedication leads to a less effective parenting strategy, for example, fleeing from parenting responsibilities. A single mother with daughters of 5 and 22 years old reported:

> *When I feel bad I leave. It does not happen very often. Last year I did this about five times. Then I took my bike and went away [F15].*

*Balancing raising children and time for oneself*

For several participants it was difficult to stay balanced in their lives. Paying attention to one's own mental health, to the housekeeping, and to relationships with friends, relatives and children must be balanced together. A mother of a 2-year-old child, who is living with a man:

> *Since I was pregnant I didn't have hobbies anymore. Once in a while I go to visit friends and family, for instance, to celebrate birthdays [F8].*

Although this is true for most people, if one is burdened by a serious mental health condition, it may be extremely challenging to keep a balance between obligations and time for oneself (i.e. time needed to cope with one's own vulnerability or take a rest). Besides the obligations of caring for their children and receiving professional support, a majority of parents stated they were hardly able to find enough time and energy for leisure activities. Like a married mother with two children of 6 and 10 years old explained:

> *I am easily tired. Sometimes I put my daughter in front of the television. And I go to sleep. Before my breakdown I did not have this [F16].*

*Using the parental role as a road to recovery*

The recovery of valued roles is an important theme. Children can change parents and, in the case of mental health problems, they can stimulate parents to develop competencies to solve problems. A 45-year-old married mother with children of 6, 10 and 12 years old explained:

> *You can be empowered by your own problems. That period offered me a lot. With my child I learned to see my own limits [F17].*

Parenting is also a good inducement for participating in social activities. A single mother with children of 5 and 7 reported:

> *My life is very busy, it revolves around the children and their friends; sports, soccer, swimming lessons … [F3].*

Being a parent in all the stages of their children's lives gave these participants strength and an identity.

*Requesting support*

Requesting support was another strategy the participants mentioned during the interviews. Support was solicited from informal resources, like relatives and friends. Also, support came through valued contacts with peers in support groups or through the internet. Often support focused on practical concerns, but also emotional support was also provided. A divorced mother with a child of 17 described:

> *It was good to talk with other parents about the limits they use for their children [F18].*

Several grandmothers played an important role in the family support and being there for their grandchildren. A 23-year-old mother living together with a man and her 1-year-old child said:

> *My mother saw that I was isolating myself, that my world became small and that I got stressed by raising my child. She said to leave him [her child] with her so I could breathe [F19].*

Requesting support from family and friends is another successful parenting strategy. It is important for parents to recognize they cannot do it all on their own, and to ask others for help. A single mother with one child of 18 reported:

> *I think I am a good survivor. Also I am very creative in imagining positive sides and advantages of new developments. Having a good network of friends that have experience with children is very important to me. I could see how to do it [parenting the child [F20].*

Although some participants rely on informal resources in the first place, others do not want to talk about their problems with their family or friends. Rather their preference is to share their concerns with professionals.

The potential positive effects of professional support are described by a married father with children of 1, 5 and 8:

> *Yes, during that parenting course in the clinic my strong capacities as a father were emphasized. This gave me self-confidence as a father [M14].*

A good combination of informal supports and professional treatment supported this individual in the parental role.

## Discussion

This qualitative exploratory study offers insight into the challenges of parents with mental illness, into the ways they bring their strengths to the tasks, and into the strategies they use to cope with these challenges. In particular, findings provide insight into the challenges faced by men living with serious mental illnesses who are fathers.

*Primary outcomes*

In general, participants reported that mental illness had a negative effect on the parental role, with increased feelings of inadequacy and the extra fear of transference of their problems to their children. Given the research on inheritance and the multi-generational transference of the risk of mental health issues for children in cases of depression, anxiety and addiction (Landman-Peeters et al. 2008; Hosman et al. 2009), it is not surprising that parents were worried about these issues.

Although all interviewed parents mentioned diverse negative effects of their mental health problems on parenting, they also found strength by meeting this role's challenges. Parents with a mental illness often feel a heightened sense of responsibility, and this helps them to stay alert when having a child. Raising one's own child offers a basis for social participation through school contacts and through the child's friendships. Developing activities that interest and engage both child and parent provides avenues for emerging strength. Despite experiencing themselves as vulnerable, these parents found a way to raise their children and enjoy this. They were all highly motivated and committed to parenting and they, overall, experienced having children and parenting to the extent possible as a positive contribution to their recovery.

As Wilson & Crowe (2009) concluded in a study with parents with bipolar disorders: Self-monitoring and self-management are important topics for anyone. Nurses can work with parents to find alternate strategies for self-management that do not feed a cycle of deficit, guilt and inadequacy. These principles of the strength programmes were the starting point of our study. Korhonen et al. (2010) reported that issues related to parenting and family life are not part of basic nursing education and basic professional qualifications but rather are developed through professional and personal growth. Working with clients who are parents and with their families should be an integrated part of the basic education of nurses.

Focusing on the role of the father, we found a few fathers who really took responsibility for their children, and were dealing with their own mental health problems in a very constructive way. For this, they sometimes needed to develop new competencies or discover lost possibilities. Where ex-partners or officials were suspicious of the effect on the children of the father's mental illness, the development of a relationship between father and child was constrained and was sometimes even used as a weapon in battles over the children. Mayberry et al. (2015a) concluded that in the gender issues fatherhood remains in the background in most discussions about families where a parent has a mental illness. The findings of our study can be used to inform a personal recovery programme for fathers with a mental illness.

Laceya et al. (2015) concluded that fathers are more likely to perceive stigma related to the impact of their gender, while mothers with severe mental illness are more likely to perceive an internalised stigma associated with their mental illness. In our study, one

father reported that his family saw him as having a contagious disease and who was not freely allowed to spend time with his daughter.

The stigma of having a mental illness and the fear of losing their parental role had a constraining effect on some of the participants. In a few cases, discrimination by family, friends, neighbours and colleagues was an impediment on the road to achieving their goals. Obtaining support and communicating openly about problems could have a preventive effect on future problems for the children.

*Strategies*

The main strategies that we found for the parental role of people with mental illness are: being fully dedicated to the parental role, finding a good balance between attention for one's own life and for parenting, and finding adequate sources of support.

Carpenter-Song & Nicholson (2012) found five themes in the ways in which parenting affects one's whole personality and life when living with mental illness. Parenting: (1) gives a person living with mental illness a positively valued identity; (2) affects interpersonal dynamics; (3) provides meaning and structure; (4) affords opportunities for growth; and (5) facilitates the exchange of positive emotions, such as love and joy. Participants in our interviews corroborated many of these themes. The women and men in our study reported that fulfilling the parental role provided a valued identity. Creating a daily routine, pursuing shared interests and activities, solving problems and finding strength in meeting parenting challenges contributed to personal growth and recovery. Relationships with children, family, school contacts and community members allowed parents to express their feelings and seek support through informal and professional networks. Successful parenting strategies were further developed through participation in self-help peer groups, and with the support of friends, family members and professionals.

Also peer-facilitators (Thomson et al. 2015), that are experts by psychiatric and paternal experience, can be trained to support parents. Parents can be stimulated to find out their own effective strategies. They like to be supported by people they recognise. Schrank et al. (2015) confirm this: Peer support may be important in parenting interventions and evidence on the feasibility and effectiveness of peer-provided parenting interventions is beginning to emerge. Reupert & Maybery (2011) emphasized the peer support programmes, also for parents with lived experience, while Salzer et al. (2010) advocated for peer specialists who are parents themselves.

The parents in our study felt capable of raising their children, despite their mental health challenges, limitations in time and energy, and other negative forces like the stigma of mental illness and parenting and associated discrimination. They needed to wash, dress and feed their children, and keep their houses in order. When their children were older, they provided companionship. Being a parent did not solve their problems; however children brought structure to their lives and opportunities for community integration and support. One way or another, they managed their mental health problems, mustered

enough time and energy, took advantage of opportunities, and developed strategies to raise children. Most participants stated that they mastered the competencies of requesting and accepting support from informal network or professionals. Still, giving birth to and raising a child was, for some parents, confusing and burdensome. For other parents, it was a part of their recovery process. Informal support seemed to be essential to these parents. In many ways, their challenges and needs are not dissimilar from those of all parents striving to be successful in this role. Family-centred practice can help to maintain and strengthen important family relationships, and to identify and enhance the strengths of a parent with a mental illness, all contributing to the recovery of the person with the mental illness (Goodyear et al. 2015).

## Limitations

This exploratory study has several limitations. First, the strong emphasis on the positive aspects of parenting could be a consequence of the fact that we recruited people for interviews who were actively, successfully parenting, and who were willing to talk about and could express themselves well with regard to parenting. This was an important research decision, however, as our goal was to shed light on strategies leading to successful outcomes for parents and children. Second, the interviews were only conducted with the parents. No children, professionals or partners were interviewed. Third, the number of participants was set at 25–30 prior to starting the study, given time and budget constraints. Consequently, we do not claim to have achieved saturation regarding topics or themes identified, we suspect, in this first exploratory study, that we have not reached saturation, and recommend further research on these topics. Fourth, steps to analyse trustworthiness with the scheme of Shenton (2004) were not executed. Results from participants' interviews are only summarized. Future research should use the scheme by recommended by Shenton.

## Implications for practice

Nurses and other professionals in health care settings must be aware of the special meaning to people with a mental illness of being a parent, the challenges they face, their vulnerabilities and increased awareness of and concern about their perceived or real inadequacies. Attention must be paid, not only to children's needs, but also to parents' attitudes, commitment and functioning. As Foster (2012) has commented on this issue: Nurses are in prime positions to support children and families. A family focused approach by nurses can be used to prevent problems for children and their families, and identify their strengths as well as vulnerabilities, address the challenges and to build resilience. Mental health nurses can learn from this exploratory study that if patients have children, they will probably be the most important part of their social network (Ackerson, 2003a). For many people parenting can be an important context for recovery and conveys a positively valued identity. Promoting parental self-confidence

and providing appropriate emotional and concrete support for everyday functioning may reinforce parental empowerment, thereby enhancing families' well-being and coping, as well as improving their access to required services (Vuorenmaa et al. 2015). In our study we found evidence of a need for this. Recovery can be initiated and coached by nurses in their various settings. Nurses can also start peer-groups with parents. Using specific parenting strategies and discovering one's own strategy can be part of it. This fits in prevention projects that have their focus on vulnerable groups and on handling stigmatization and discrimination (Hosman et al. 2005). And as Enns et al. (2016) stated it: health policies and promoting prevention of mental illness in the general public are under-recognized facets of primary prevention. Increasing awareness and adoption of such strategies could reduce the burden of mental illness in individuals, families, communities, and society. This is confirmed by Fernandez et al. (2016) by the statement: there is a lack of implementation and/or evaluation of mental health promotion activities conducted by primary care professionals. More research is needed to clearly understand the benefits of promoting mental health in this setting.

The fathering role requires special attention. As direct contact seems to be highly beneficial for developing adequate role functioning and positive relationships with children, spouses or partners should be encouraged to allow fathers opportunities for contact and caring. Fathers who may be out of work will have more time available to be with their children and contribute to raising them.

Mothers and fathers can be supported by interventions provided by nurses in which patients are identified as parents, and self-chosen parenting related goals are set and worked upon.

Programmes for all parents can be found, for example the Positive Parenting Programme (Triple P., Sanders et al. 2014), that gives parents practical strategies to help them confidently manage their children's behaviour, and build strong, healthy relationships. If there is a need for these specific strategies it is also relevant for parents with a mental illness. For fathers special Triple P. programmes are developed (Fletcher et al. 2011). The so called 'Stepping Stone Triple P' is used for parents of children with borderline to mild intellectual disability (Kleefman et al. 2014). If a part of this program can be used for the group of our study is unclear, but a lesson to be learned is that there is a high dropout in attending the programme. Parents with drugs or alcohol-related problems can be supported by the programme 'The Incredible Years' (Leijten et al. (2015) and for young addicted parents 'The parents under pressure programme' (Barlow et al. 2013). As an early intervention there is the programme 'Mellow Parenting'. This is a more specific family of parenting and relationship programme developed to support parents and their young children in making good relationships (Puckering et al. 1994; www.mellowparenting.org). Since addiction is closely related to mental illness programmes may go together or at least professionals who work with these programmes can learn from each other.

For parents with mental illness also several specific programmes are developed. Cook & Mueser (2014) observed a new generation of recovery-oriented Psycho-Social Rehabilitation services for mothers and fathers. Opportunities for enhanced services are provided in particular by self-help, peer support programmes for parents with lived experience (Hinden et al. 2006, Reupert & Maybery 2011, Van der Ende et al. 2014, Schrank et al. 2015). These programmes are recovery-oriented and more aimed at the attitude of the parents than on the behaviour of the children. As a difference with the former programmes for parents these programmes do not have a deficit approach with an emphasis on problems and pathology. The programmes are not fitting parents and children into preexisting service plans.

Providers of all types, mental health, medical, and social service, and school personnel can be encouraged to focus on family strength (Reupert & Maybery 2014). Parents living with mental illness can be encouraged to share ideas with other parents, and to engage in talking about parenting concerns, to benefit from peer support (Hinden et al. 2006, Reupert & Maybery 2011, Van der Ende et al. 2014). Nurses may serve as good role models for parenting as well.

People without mental health problems may face comparable issues in their parental role. A future study comparing these diverse groups of parents could explore their experiences, with an eye to optimizing the parenting experience for all adults and their children. Also attention should be paid to the topic of how fathers and mothers can divide tasks and learn from each other's strengths in situations of parental mental illness.

## What the exploratory study adds to existing evidence

Our study can be seen in the light of a growing attention for a more rehabilitative approach towards those who are patients and parents. From this point of view several studies addressing parental needs have been conducted (Nicholson & Deveney 2009, Howard & Underdown 2011, Reupert & Maybery 2011). Parallel to this line of research, supported parenting programmes were developed and evaluated (Nicholson et al. 2001, Hinden et al. 2006; White et al. 2013; Cook & Mueser 2014). Most recently Aldersey & Whitley (2015) conducted a study on the role of family members on recovery and found that, apart from practical support, the family also may give moral support and functions as a motivation for recovery. Other researchers also studied recovery in the context of parenting (Topor et al. 2006; Carpenter-Song & Nicholson 2012; Bonfils et al. 2014; Maybery et al. 2015b). However, taking the strength and the opportunities formulated by parents themselves as a starting point is fairly new, and no studies were found that focus mainly on strategies that are formulated by these parents themselves. In this study these strategies were found to be the fundamentals of recovery related to parenting. Several types of strategies are distinguished in this study: being fully dedicated to the parental role, finding a good balance between attention for one's own life and for parenting, and finding adequate sources of support. This leads to a new advice for nurses and other

professionals in health care settings: Focus on existing and self-developed strategies in parenting to reach an optimum situation in case of parental mental illness. If needed professionals can serve as one of these sources of support and so help to find the balance needed. However more important is their help in facilitating parents to find their own way of managing the challenges of parenthood.

## Conclusion

Mental health problems can be a factor when faced with the challenges of parenthood. From the accounts of parents in this situation, the following strategies can be successful: the choice to fully dedicate oneself to the parental role, finding a good balance between attention for one's own life and for parenting, and finding adequate sources of support. Although most fathers felt limited in their role, examples showed that fathers with mental health problems can find ways to play a bigger role. As direct contact is a prerequisite for developing adequate role functioning and positive relationships with children, spouses or partners should be encouraged to allow fathers' opportunities for caring.

# CHAPTER 4

## PROFESSIONALS' OPINIONS ON SUPPORT FOR PEOPLE WITH CHRONIC ILLNESS IN THEIR ROLES AS PARENTS IN MENTAL OR IN GENERAL HEALTH CARE

**This chapter is based on the article:**
Van der Ende, P.C., Van Busschbach, J.T., Korevaar, E.L. & Van Weeghel, J. (2017). Professionals' Opinions on Support for People with Chronic Illness in their roles as parents in Mental or in General Health Care. *American Journal of Psychiatric Rehabilitation 20(1), accepted.*

## Abstract

Chronic illness afflicts a person's wellbeing and affects the ability to perform the social roles of spouse or parent. When working with people with long-lasting mental or somatic illnesses, social workers and nurses are confronted with needs for support, especially for parents. Although programs are in place for the children of parents with chronic illnesses, specific services for the parents themselves are scarce, as are parenting support courses for professionals. In an explorative study we investigated the similarities and differences between mental health organizations and general hospitals in providing support to parents.

Using a cross-sectional design, information on supported parenting was collected through an internet questionnaire. Professionals in general hospitals found themselves more able to provide support to parents than did those in mental health organizations that were not trained in supported parenting. Professionals in mental health institutions generally reported that the attention paid to the parental role is insufficient. However, professionals in mental health organizations who were trained in supported parenting considered paying attention to the parental role more as a part of their job than the participants from organizations without such a training. Further research should expand this first pilot study on the attitude of professionals towards supported parenting.

## Introduction

Chronic illness, including some mental illnesses not only afflicts a person's wellbeing but can also have great impact on the ability to perform social roles as a spouse or a parent. Social workers and nurses are confronted with their patients' needs for support and advice, especially when children are involved. The number of parents with chronic illness is relatively large in mental health care. Research in various high income countries shows that one quarter to over half of the people with severe mental illness are parents. The highest percentages were found in the US and UK: In the US, a study by Nicholson, Biebel, Williams, & Katz-Leavy (2004) reported 67% of people with severe mental illness to be parents whereas Howard, Kumar & Thornicroft (2001) showed that 63% of the women with psychosis in Great Britain have children. In the Netherlands and Australia these percentages are lower, respectively 48% (Van der Ende, Van Busschbach, Wiersma, & Korevaar, 2011) and 25–28% (Howe, Batchelor & Bochynska, 2012) but still substantial. In the general population more than 57% of people between 18-65 years have children (Office for National Statistics, 2011) and the proportion of people in general hospitals with chronic illness who have children is likely to be the same.

In psychiatric research, the challenges faced by parents with severe mental illness have drawn increasing interest (Mowbray, Oyserman, Bybee, MacFarlane, & Rueda-Riedle, 2001; Nicholson et al. 2004; Nicholson & Deveney, 2009; Wansink, Hosman, Janssens, Hoencamp, & Willems, 2014). However, while programs exist for 'Children of Parents with Mental Illness' (COPMI, Orvaschel, Walsh-Allis, & Ye, 1988;Stiffman, Earls, Robins, & Jung, 1988; Thomas, Forehand, & Neighbors, 1995; Ackerson, 2003b; Van Doesum, Riksen-Walraven & Hosman, 2008), specific services for parents are scarce, as are programs to train social workers and nurses on how to support people with chronic illness in their roles as parents (Hinden, Biebel, Nicholson, Henry, & Katz-Leavy, 2006). The need for care in this area is reflected in a recent study in which half of the responding parents with psychiatric disabilities reported that they wanted types of support that regular mental health care did not supply: for example nurturance support, legal assistance with custody and child support and arranging for support from peers (Van der Ende, Venderink, & Van Busschbach, 2010). However, adequate social support is not always available because fear of stigmatization often renders the topic off-limits and leads to secrecy and concealment (Hinshaw, 2005; Thornicroft et al. 2009).

In general health care, family-centered care and nurses who attend to the needs of the children are needed (Coyne, O'Neill, Murphy, Costello, & O'Shea, 2011). The importance of the role nurses play is indisputable, especially in the case of chronic or fatal illness, when children must cope with the threat of losing their parental care (Helseth & Ulfsaet, 2005; Huizinga et al. 2005). Parents with cancer have feelings of guilt about not being good parents, and they struggle to know how they should talk to their children about cancer (Semple & McCance, 2010).

However, because the parent is the “patient”, the primary attention of health professionals remains focused on him or her (Huizinga et al. 2005). Although a special group program for parents with cancer was developed recently (Hasson-Ohayon & Braun, 2011), the efforts taken to address the psychosocial aspects of living with parental cancer are mostly still in their infancy (Syse, Aas, & Loge, 2012). In this article, the professional support of any aspect of parenting is called “supported parenting.” This term does not refer to a special program and it includes the non-systematic support of parents by professionals. Also, all different kinds of parenting are included. It applies to the tasks and skills of parents that share their roofs with their children and have 24 hours responsibility for them but also to the needs of others who only see their children once in a week or less while others have only sparse face to face contact because of long term hospitalization and in the worst case scenario know that because of terminal illness will not see their children grow up.

Information about the need for supported parenting and for special programs can be found in several studies (Göpfert, Webster, & Seeman, 2004; Hinden et al. 2006; Syse et al. 2012). To what extent different professionals in general health care provide this support is unknown. Most of the described programs are family-centered and strength-based, and some use case management as a starting point. According to the study by Hinden et al. (2006) no programs have been researched in outcome studies, indicating that these programs are not evidence-based. Furthermore, Korhonen, Vehviläinen-Julkunen, & Pietilä (2008) claim that most nurses in general hospitals support the wellbeing of parent patients and talk with them about their children. However virtually no studies can be found on the role of professional workers in supporting parental responsibilities in the context of adult psychiatry (Korhonen, et al. 2008).

This study addresses the question whether hospital staff members provide supported parenting to their patients and especially whether the given support varies between mental health facilities and general hospitals. Different parental support practices are investigated. This was also done with a focus on possible differences between the staff members in organizations who were trained in supported parenting and those who were not. This comparison provides a snapshot of the availability of supported parenting and identifies organizations that can serve as an example for other organizations.

## Methods

*Participants*

The first group (n=41) of respondents in this study comprised of workers in two provincial Dutch mental health organizations where professionals had previously received a four-day training in the parenting support program called PARSS (See Appendix 2 and also Van der Ende et al, 2014). This program is a recovery and psychiatric rehabilitation-based, guided self-help intervention for parents with severe mental illnesses that was

inspired by the rehabilitative approach used by the Psychiatric Center of Rehabilitation of Boston (Farkas & Anthony, 1991). The approach comprises a methodology that helps parents explore, choose, and realize their goals in the areas of parenting. Depending on his or her needs and preferences, a parent in recovery is supported in the parental role in conjunction with different aspects of life such as achieving a balance between holding a job and housekeeping and finding time for rest and recreation. The second group of respondents (n=36) consisted of professionals from two nearby mental health organizations where no such training had been offered. In the four mental health organizations of these two groups, workers from a variety of departments (long stay/short stay, inpatient/outpatient care) were approached. The third group of respondents (n=51) included health workers from three Dutch general hospitals from long-stay departments with specialties such as oncology, pulmonary illness and burns. All organizations were located in the northern part of the Netherlands, which is mainly a rural area with a few larger cities.

Workers from various disciplines responded to the invitations: including 54 nurses, 49 social workers, 9 psychologists, 8 physicians and 8 from other disciplines (see Table 1). No special family therapists were found in this group. In our general hospital sample, most professionals are nurses, while in the mental hospitals more social workers are found.

**Table 1 Discipline of the Participants in the Research Group (N = 128)**

| | Mental health organizations | | General hospitals | Total |
|---|---|---|---|---|
| | trained# | not trained | | |
| | n = 41 | n = 36 | n = 51 | n = 128 |
| Disciplines | | | | |
| Social Worker | 29 (71%) | 8 (22%) | 12 (24%) | 49 (38%) |
| Nurse | 8 (20%) | 11 (31%) | 35 (69%) | 54 (42%) |
| Psychologist | 1(2%) | 8 (22%) | 0 | 9 (7%) |
| Physician | 1 (2%) | 5 (14%) | 2 (4%) | 8 (6%) |
| Other | 2 (5%) | 4 (11%) | 2 (4%) | 8 (6%) |

# in supported parenting.

Differences were identified between the organizations with regard to the professional backgrounds of the participants. Social workers who were trained in supported parenting were mainly associated with the mental health organizations in which such training was offered. In the mental health organizations that did not offer such training, the participants were nearly equally divided among the disciplines.

*Measures*

To shed more light on how workers think about supporting people with chronic illness in their parental role, a questionnaire was designed specifically for this study. Questions addressed the support given to parenting and the content of the interactions concerning the parental role that occurred between the staff and people with chronic illness. Examples of the questions include the following: “What do you think of the attention to parenting that is paid by your organization”, “Supported parenting is an important topic”, “Supporting parents is part of my job”, “Do you pay attention to the functioning of the children” and “What type of contact do you have with your patients: treatment, support, giving information.

One question about the themes of the support was extracted from an instrument on parenting by Kendall and Bloomfield (2005): “What parental role subjects do you pay attention to?” with the answering categories ‘emotions’, ‘empathy’, ‘social contacts’, ‘tensions’, ‘acceptance’, ‘boundaries’, ‘control’, ‘play with children’, ‘knowledge of services’ and three categories added ‘contacts with services’, ‘balance’ and ‘talk with children’. The respondents were instructed to choose the three items that were most important in the care they provided to parents. In table 3 answers were put together two by two. Scale analysis showed this question on “The content of the contact about the parental role” between professionals and parents to be an acceptable scale with Cronbach’s $\alpha = .7$. Next a categorical question was asked concerning why the workers were able to pay attention to parenting with answers such as “enough knowledge” and “competent to offer support’.

At the end of the questionnaire, a few open questions on supported parenting were asked. General information about the department, discipline and characteristics of the people with chronic illness were also gathered. Questions referring to the characteristics of workers such as age and work experience were omitted to create a brief questionnaire that could be completed in seven minutes on average. Because this was a new questionnaire with an explorative character, the subjects were diverse as were the ways in which the responses were categorized.

*Procedure*

Several managers of the Hanze University of Applied Sciences had work contacts with managers in the health organizations and after an invitation letter, emails were sent by people from these organizations to the professionals with a request to participate in this study. Selection of organizations was based on whether or not training on supported parenting was offered and the region. All of these centers were nonprofit organizations. After receiving an invitation through email, 128 people completed web-based questionnaires.

*Design*

For this explorative study, a cross-sectional design with three pre-formed groups of respondents was chosen to explore the differences between general hospitals and mental health organizations in terms of the resources available for supporting parents and the competence of its workers in talking about parenting and giving support.

*Analysis*

For the statistical analyses, the software program SPSS-22.0 (IBM Corp., 2013) was used to compute Cronbach's $\alpha$ to test reliability of a scale and chi-square statistics to compare responses among the groups. The Bonferroni correction was used to counteract the problem of multiple comparisons.

## Results

*Support for Parental Role*

The first part of Table 2 shows how respondents perceived their organizations' attitudes toward parental support, in answer to the questions like: "What do you think of the attention to parenting that is paid by your organization" and "Is the support seen as a part of the job?" The second part of the table shows how competent they felt as professionals to provide parental support.

**Table 2 Perceptions of Supporting Parents (% confirmative answers) N=128**

| | Mental health organizations | | General hospitals |
|---|---|---|---|
| | trained [a] | not trained | |
| | n = 41 | n = 36 | n = 51 |
| Organization | | | |
| Organization pays enough attention to parenting | 25 (61%) | 9 (25%) | 37 (73%)*1 |
| Parenting is an important topic | 16 (39%) | 11 (31%) | 18 (35%) |
| Enough time is provided to support parents | 13 (32%) | 2 (6%) | 19 (37%)*2 |
| Supporting parents is part of my job | 30 (73%) | 22 (61%) | 26 (51%) |
| Professionals | | | |
| Enough knowledge on supporting parents | 13 (31%) | 9 (25%) | 11 (21%) |
| Competent for supporting parents | 20 (49%) | 12 (33%) | 26 (51%) |

*Note.* The p-values were checked with Bonferroni's multiple comparison calculation

*1. $\chi 2 = 20.0$ df = 2 $p < .001$

*2. $\chi 2 = 11.7$ df = 2 $p = .003$.

[a] in supported parenting.

*Perceptions of supported parenting*

In the general hospitals, 73% found that their organization paid sufficient attention to parenting. In the mental health organizations where training in supported parenting was given, 61% of the professionals stated that their organization adequately facilitated parental support. However, in mental health organizations without such training, significantly fewer professionals, 25%, felt that their organization paid enough support to the parental role of patients.

No differences between organizations were found in the importance of the topic: of all the participants, 31% to 39% rated supported parenting as one of the three most important topics. In comparisons with the other groups significantly fewer professionals from the mental health organizations without specific training reported that they had enough time for this type of support. Over 50% of the professionals surveyed stated that at their organizations, supported parenting was considered part of their jobs, and there were no significant differences between groups in this respect.

*Competence in providing supported parenting*

When the participants were asked why they discuss parenting with chronically ill patients, in an open-ended question some answers were included: “We offer the whole package, and caring for people with chronic illness can’t be done without paying attention to the children,” and “If a parent is limited in handling their children, we make it a part of their treatment plan.” Reasons for not discussing parenting were related to time or to the fact that the parents had no unmet needs in this area. Furthermore, the respondents noted some special reasons for participants not to discuss this subject. One respondent wrote: “Parents in general do not express that they have problems with parenting. The focus is more on the actual problems.” Another participant wrote: “The parent will be referred to a family-therapist or to another organization, such as Children and Youth Services.”

There were several answers to the question about why professionals felt they provided adequate supported parenting. At the mental health organizations that trained their staff in supported parenting, 31% of the participants reported that they had sufficient knowledge to provide supported parenting. This percentage was lower in the mental health organizations without training and in the general hospitals (25% and 21%, respectively).

Respondents also reported that competence was a reason why they provided adequate supported parenting. Forty-nine percent of the staff in the mental hospitals with past training and 51% of the staff in the general hospitals indicated they felt competent as compared to 33 % of the staff in the mental hospitals with no past parental support training.

*Type of contact*

Table 3 shows the type of contact between the mental health worker and the parent, for example, as part of treatment or informative.

**Table 3 Type of Contact in Supported Parenting by Health Workers (% confirmative answers) N=128**

| | Mental health organizations | | | | General hospitals | |
|---|---|---|---|---|---|---|
| | trained# n = 41 | | not trained n = 36 | | n = 51 | |
| Type of contact | | | | | | |
| Treatment | 31 | (76%) | 20 | (56%) | 34 | (67%) |
| Support | 16 | (39% | 14 | (39% | 32 | (63%) |
| Providing information | 4 | (10%) | 1 | (3%) | 7 | (14%) |

*Note. Numbers in parentheses indicate column percentages.*

# in supported parenting

No significant difference between the organizations was found in the amount of treatment-orientated versus support-oriented contact reported. General information about parenting was provided by 3% to 14% of the workers. Supported parenting was described by some of the participants as part of the treatment plan aimed at recovery; however, others classified supported parenting as a form of general supportive care to help people with chronic illness cope with everyday life.

*Content of Contact*

Table 4 shows the different subjects that were discussed by professionals with patients who are parents and gives an impression of the content of the contacts between health professional and these parents.

**Table 4. Content of Contact in Supported Parenting by Health Workers (% confirmative answers) N=128**

| | Mental health organizations | | | | General hospitals | |
|---|---|---|---|---|---|---|
| | trained# n = 41 | | not trained n = 36 | | n = 51 | |
| Content of contact * | | | | | | |
| Emotions and empathy | 18 | (44%) | 15 | (42%) | 33 | (65%) |
| Social contacts and balance | 24 | (58%) | 18 | (50%) | 18 | (35%) |
| Tensions and acceptance | 18 | (44%) | 13 | (36%) | 24 | (47%) |
| Boundaries and control | 23 | (56%) | 18 | (50%) | 13 | (25%)** |
| Play and talk with children | 18 | (44%) | 14 | (39%) | 23 | (45%) |
| Knowledge and contacts with services | 20 | (49%) | 8 | (22 %) | 12 | (24%) |

*Note.* More than 1 answer per person was possible. Numbers in parentheses indicate column percentages. The p-values were confirmed with Bonferroni's multiple comparison calculation

# in supported parenting

*Cronbach's $\alpha$= .7

**$\chi^2$ = 10.0, df = 2, p < .001

"The content of the contact about the parental role" between professionals and parents offered an acceptable scale (with Cronbach's $\alpha$ = .7) in this study. Most support for parents was aimed at promoting emotional connections with the children. Subsequently, professionals addressed subjects related to upbringing, such as setting boundaries and control. Possibly because of the differences in the needs of the parents at hand, staff in the mental health organizations, paid significantly more attention to these subjects, compared with the participants from the general hospitals. There was a significant statistical difference for the variable 'boundaries and control' among these settings. In general hospitals most professionals are nurse, while in the mental hospitals more social workers are found. This significant difference may have occurred due to the different professional identities of these staff members, but no other significant differences in supported parenting were found between these disciplines.

## Discussion

In all participating mental health organizations and general hospitals more than one third of the workers who participated in the survey rated supported parenting as one of the three most important topics. Although this survey was not an evaluation of the staff training (that was conducted in another study, Van der Ende et al. 2014), some tendencies were apparent. Participating professionals in settings with previous training had more knowledge and felt as competent as the workers in our sample in the general hospitals and more competent than those in the mental health organizations without training.

The study indicates that supporting the parental role is possibly less present among the professionals in mental health organizations than in general hospitals and this was opposed to what we expected. In the mental health organizations where training in supported parenting was provided, over half of the participants stated that they had adequate time for supported parenting, whereas in untrained mental health organizations, significantly fewer participants could find time to pay attention to the parental role.

The primary attention of mental health professionals in our sample appeared to be focused on the person with a chronic mental illness; support for the parenting tasks was not generally a component of patient care. More than these respondents, those in general hospitals focussed not only on the physical health of the patients but also on the children and parenting in cases of serious and long-term problems. In terms of benchmarking, the general hospitals seem to have a lot to offer in ways of supported parenting.

The strength of this study is that it describes a wide variety of health workers' possibilities and competencies for supported parenting and the influence of the context and training on supported parenting. No previous reports have directly compared general hospitals and mental health organizations.

A selection bias may have contributed to these results. Respondents from both types of mental health organizations and the general hospitals could have chosen to participate in this study because they had a preexisting interest in supported parenting. A more random inclusion could have led to different results. A selection bias may have contributed to these results and limits their generalizability. Respondents from both types of mental health organizations and the general hospitals could have chosen to participate in this study because they had a preexisting interest in supported parenting. A more random inclusion could have led to different results. For now this study should be regarded as a first explorative study and with only limited value where the opinion of other professionals in the same or other hospitals are concerned. For practical reasons, additional information concerning the characteristics of the respondents was limited to their work environment. By thus omitting individual characteristics such as age and work experience, we are unable to determine how such characteristics may have influenced responses and consequently, the results of the study. New studies are required to determine whether the significant differences exist in larger representative samples, too.

The possibility of bias is particularly strong because the study was conducted through a web-based internet questionnaire. Since emails with invitations to participate were spread in the organization no random selection but a self-selection by participants took place. The liabilities associated with samples obtained from the internet are not likely to be much greater than the weaknesses associated with traditional recruitment methods, such as the trade-off between internal validity and generalizability (Lieberman, 2007). The results of a study by Gosling, Vazire, Srivastava, & John (2004) suggested that valid and reliable data can be obtained when the population is accessed via the internet. Currently, doubts exist concerning the generalizability of the outcomes of this type of research. Because online scientific studies do not belong to an established research tradition, additional techniques must be developed to gain insight into variables such as non-response and the bias caused by selecting patients who are 'online'. However, the cited articles indicate that the results of online research can be generalized with the same cautions applicable to other types of research in which no absolute response is guaranteed. Although information about the non-participants is missing, internet-based findings are consistent with findings based on traditional methods (Walker, 2013).

Another limitation was the use of an unvalidated questionnaire for this online study because no validated instruments were available. To promote a greater number of responses, the new questionnaire was quite short. Because the study was a descriptive pilot, only nominal data were gathered. Validity was augmented by the fact that professionals could answer anonymously.

No insight was obtained on possible differences between male and female professionals with regard to supporting their patients' parenting. In general hospitals most professionals were nurses, while in the in supported parenting trained mental health organizations more social workers were found and the other mental health organizations had an equal number of these disciplines. No significant differences on all variables were found between nurses and social workers. Still the distribution of disciplines of workers might have been a confounding factor.

The conclusion from this small explorative study that supported parenting was insufficiently available in mental health organizations in the Netherlands contrasts with research findings from Finland, where more than 90% of the nurses in the psychiatric units of five Finnish hospitals took the initiative to talk about children with their patients and were aware of the importance of a family support network and a stable family environment (Korhonen, Vehviläinen-Julkunen, & Pietilä, 2010). Our study however gave evidence that a training in supporting the parental role in mental health organizations can give a contribution to parental support in the eyes of the professionals. After all we did find that professionals from mental health organizations who were trained in supported parenting described it as part of their job more frequently than did the participants from organizations where no such training was provided. Professionals in mental health organizations generally found the attention paid to the parental role to be insufficient.

However, professionals from mental health organizations who were trained in supported parenting described it as part of their job more frequently than did the participants from organizations where no such training was provided. This might give evidence that a training in supporting the parental role in mental health organizations can give a contribution to parental support in the eyes of the professionals. Several supported parenting programs for care providers have already been developed (Hinden et al. 2006; Reupert & Maybery, 2009; Van der Ende et al. 2010), which could be implemented by existing facilities. Recently, a program was developed that focuses on both parents and children (Wansink et al. 2014). In addition, internet programs are available (Kaplan, Solomon, Salzer, & Brusilovskiy, 2014).

As for now this study indicates that the specific parenting support needs of patients with chronic illnesses are possibly better met in general hospitals than in most mental health centers. In these organizations, training professionals in supported parenting can have a positive influence on the amount of attention paid to the challenges patients face as parents.

To complete this research, quantitative and qualitative data will be needed about how parents with mental illness, both fathers and mothers, experience and reflect on the available professional support. Further research should expand this first pilot study on the attitude of professionals towards supported parenting with a representative sample of both social workers and nurses, focusing on the influence of training on competence and actual behavior.

The mental health organizations are advised to make supported parenting available to all patients who need it and to provide staff with sufficient competencies in this type of support. Individual care plans should be designed to include support for parents. In this plan the personal network and professional workers in an outpatient setting after the parent's discharge should also be involved in the parents' care.

# CHAPTER 5

## PARENTING AND PSYCHIATRIC REHABILITATION: CAN PARENTS WITH SEVERE MENTAL ILLNESS BENEFIT FROM A NEW APPROACH?

**This chapter is based on the article:**

Van der Ende P.C. , Van Busschbach J.T., Nicholson J., Korevaar, E.L. ,Van Weeghel, J.(2014). Parenting and psychiatric rehabilitation: Can parents with severe mental illness benefit from a new approach? *Psychiatric Rehabilitation Journal, Vol 37(3), Sep 2014*, 201-208

## Abstract

**Objective:** The aim of this pilot study was to explore the initial experiences with and impact of Parenting with Success and Satisfaction (PARSS), a psychiatric rehabilitation and recovery based, guided self-help intervention, for parents with severe mental illnesses.

**Methods**: Changes in the PARSS intervention group (N=11) were compared with changes in a control group (N=15) in a nonequivalent control group design. Outcome measures included: parenting satisfaction reported by parents; parenting success reported by mental health practitioners and family members; empowerment as reported by parents, practitioners and family members; and parents' reported quality of life. Additional process data were obtained on relationship with practitioner, quality of contact, satisfaction with the intervention and fidelity.

**Results:** Parenting satisfaction increased after 1 year for the PARSS group, but not for the control group. Parents' reports of empowerment did not change for either group. The scores of parents' empowerment reported by practitioners and family members increased in the control group, with no such change in the PARSS group. Quality of life improved significantly for the intervention group. Process measures showed that, although PARSS was not always implemented as intended, both parents and practitioners expressed satisfaction with the intervention.

**Conclusions and Implications for Practice**: The first experiences with PARSS were mixed. This intervention, implemented by mental health practitioners, has the potential to function as a useful tool for supporting parents. Attention must be paid to enhancing intervention implementation and fidelity.

## Introduction

Parents with disabilities living with severe mental illnesses, like all parents, face a variety of challenges when raising children. With the shift from hospital-based care to community-based mental health programs and a growing awareness of the need to live life according to one's own choices, there are most likely increasing opportunities for people with severe mental illnesses to become parents and care for their children. In the U.S., about two thirds of people meeting criteria for severe mental illness living in the community had children (Nicholson, Biebel, Williams, & Katz-Leavy, 2004). In the Netherlands, we estimated that 48% of the population living with severe mental illnesses were parents of children under 18 years of age (Van der Ende, Van Busschbach, Wiersma, & Korevaar, 2011).

In the past 10 years, the parental role has received increased attention in psychiatric rehabilitation (Ackerson, 2003a; Mowbray, Oyserman, Bybee, MacFarlane, & Rueda-Riedle, 2001). Several authors emphasize that rehabilitation approaches should address the needs of the person in recovery as a parent (Howard & Underdown, 2011; Nicholson & Deveney, 2009). Positive as well as difficult aspects of parenting for adults living with psychiatric disabilities are emphasized by these authors. They and others explored parents' challenges and over the years they developed supportive strategies and programs for parents with psychiatric disabilities (Craig, 2004; Nicholson, Henry, Clayfield, & Phillips, 2001) and evaluated those (Nicholson, Albert, Gershenson, Williams, & Biebel, 2009). Practitioners providing related evidence-based interventions for adults with mental illnesses are aware of the issues for adults as parents. For example, Assertive Community Treatment programs have been studied as they provide services to parents with mental illnesses (White, McGrew, & Salyers, 2013). More recently, Jones et al. (2013) introduced online parenting programs for Internet use.

The research focus shifted from the adverse effects of parental mental illness on children toward consideration of the experience and needs of mothers and fathers living with mental health problems, and the development of strategies to support their integration into family and community life (Nicholson, Nason, Calabresi, & Yando, 1999). Addressing parenting issues in conjunction with parents' mental health needs was concluded to be important when working with this group (Reupert & Maybery, 2011). Authors also recommended numerous parent-focused services, including family therapy, parenting skills, communication skills training, accessing resources for children, and peer support groups (White et al., 2013; Hinden, Biebel, Nicholson, Henry, & Katz-Leavy, 2006; Nicholson et al., 2001). In addition to standardized programs for well parents, there is a need for an approach that can support parents living with mental illnesses in focusing on their parental role if they choose, and on the goals for family life they select and prioritize.

The Parenting with Success and Satisfaction (PARSS) intervention has been developed to this end (Van der Ende, Venderink, & Van Busschbach, 2010). This approach comprises a method that helps parents to explore, choose and realize their rehabilitation

goals in the area of parenting. The aim of PARSS is to support individuals in developing skills and accessing the resources necessary to be successful and satisfied in their chosen role and life context—that is, parenthood and family life. Depending on his or her needs and preferences, a parent in recovery is supported in developing capabilities as a parent along with addressing other life roles and goals. For instance, a parent in recovery may be supported in achieving a balance between holding a job and housekeeping, or finding time for rest and recreation while meeting the demands of parenting.

Psychiatric rehabilitation has been shown to be an effective approach to enhance social functioning, housing stability and societal participation (Swildens et al., 2011; Gigantesco et al., 2006; Shern et al., 2000), but has not yet been widely studied in the context of parenting and parents' goals. In this paper, a small-scale pilot feasibility study is described. We examine the initial experiences with and impact of the PARSS intervention on parenting satisfaction and success, and on empowerment and quality of life for parents living with serious mental illnesses, compared with those receiving care as usual. This pilot study is intended not only to explore the benefits that can be gained from participation in PARSS, but also to identify adequate procedures and measures for implementing and evaluating an intervention of this type.

*The PARSS Intervention*

Key elements of the Parenting with Success and Satisfaction (PARSS) intervention include: (a) the psychiatric rehabilitation framework (Farkas & Anthony, 1991); (b) a focus on enhancing self-regulation (Sanders & Mazzucchelli, 2013); (c) structured strategies for proactive service to reach out to parents who express a need for support rather than waiting for a problem or crisis to occur (Weir, 2004); and (d) a transdiagnostic approach that suggests that certain fundamental processes underlie or transcend multiple psychiatric diagnoses. The intervention explicitly targets parental emotional regulation rather than diagnostic-specific characteristics as a useful strategy in developing interventions for families (Maliken & Katz, 2013).

In the PARSS intervention, parenting is seen as a valued social role that is defined by individuals in their own ways. There is an explicit awareness of and respect for both the needs of the children, and the choices and constraints of their parents. Emphasis is placed on communicating well with others who are important to the parent and the child. Attention is also paid to effective communication with more formal supports, such as school personnel or representatives of agencies providing foster care to children. Parents may be reluctant to seek support from others—relatives or professionals—because they fear the negative attitudes and assumptions of others and possible loss of custody; this concern is discussed with parents before they begin the intervention.

PARSS is seen as an addition to other types of treatment and may be implemented in either inpatient or outpatient settings (Van der Ende et al., 2010). The training of mental health practitioners to implement PARSS takes a total of 4 days, with longer intervals

between sessions in the last phase of the training. This is done to facilitate clinical supervision of the mental health practitioners when they start coaching. The PARSS intervention includes three workbooks for parents to help them achieve their parenting goals in a guided self-help approach. For parents, PARSS provides a way of working on self- selected goals for one's own well-being, in combination with a focus on the child's strengths and needs. Components of the intervention may be used by parents themselves as a self-help strategy. Other components of the intervention are best completed with the assistance of mental health practitioner (i.e., a social worker nurse or psychologist and, in some cases, psychiatrist).

**Workbook I. Assessing functioning in the parental role**
This workbook lays out explicit skills and recommended resources for carrying out the parental role for all parents. The chapters in this component are: Identity; Satisfaction and Success; Division of Time; and Attention and Commitment.

**Workbook IIa. Strengthening the parental role**
With the help of this workbook, parents who are living with their children are encouraged to describe what the parental role means to them. Workbook sections include: What does the Parental Role Ask of Me? Can I Satisfy These Demands? And Overcoming Barriers.

**Workbook IIb. Taking back or expanding the parental role**
This is designed for parents not living with their children. It focuses on exploring opportunities and situations specific to parents who live separately from their children. Based on the values and needs of the parent, opportunities and situations for dealing with the child are explored, particularly given that parents are not currently living with their children. The components are: My Needs as a Parent; The Possibilities for Me as a Parent; What Do My Choices Require? Can I Meet These Demands? Overcoming Barriers; and How to Go On.

Parents progress through the PARSS Workbooks with a mental health practitioner in ways that are adapted to their own situations and preferences, individually or in groups. In individual contact, work on parenting goals can be combined with a focus on other goals. If contact between a practitioner and a parent has a single emphasis on parenting goals, the entire intervention takes about a year on average, with weekly sessions. Before beginning the intervention, parents are informed of this commitment. PARSS is relevant to parents who are raising their children themselves, or to parents who have contact with their children through a custody and visitation arrangement. PARSS may also be useful to parents during or after a psychiatric hospitalization.

## Methods

This pilot study employed a nonequivalent control group design. We used this design instead of a randomized control design that is more common in evaluation research. This was done for different reasons. Because of the risk of spillover, parents in contact with mental health teams with professionals trained in PARSS were only assigned to the experimental group. For the control group parents were included who had only been in contact with workers without a training. It was expected that, in the teams with PARSS-trained practitioners, an insufficient number of participants with an expressed need for rehabilitation support in parenting would be found for random allocation to either the intervention group or the control group. As a pragmatic solution, we chose to find parents with such an expressed need for support on parenting for the control group in organizations with practitioners who were interested but who had not received any training in PARSS. The design and accommodations were justified by the study focus on the pilot nature of the intervention.

*Recruitment of Participants*

PARSS training was provided in four mental health organizations. Practitioners could choose to participate in this training. Once they were trained, practitioners were asked to refer parents to the intervention group for the study. Only parents who explicitly stated they needed support in parenting were selected for participation in the study. The intervention group consisted of parents enrolled in PARSS. Four comparable mental health organizations in other parts of the Netherlands were asked to refer parents for the control group.

Recruitment was done in teams for long term care so as to select the specific group of especially parents with severe mental health problems. Parents with at least one child younger than age 21, who received mental health care and expressed a need for support in parenting issues, were recruited. In addition parents in the experimental group had to be willing to be coached by their mental health worker along the lines of the PARSS program. Since at the time of the evaluation study around 100 mental health professionals were trained in six organizations.

In four organizations permission was granted to perform the study. From these organizations parents were recruited for the experimental group. In four other organizations professionals and parents were recruited to form the control group. One contact- person per organization was central and he or she was in contact with her (trained) colleagues. At the time a patient gave consent to participate the parental program with a patient started this was communicated with the researcher. The mental health practitioner working with the parent participated in an interview and parents were also invited to recommend a significant member of their network (e.g., a close family member) to be interviewed for the study. After this the trained professionals and parents in the experimental group started the PARSS program. In the control group professionals,

not trained in this program, continued to work with the parent 'as usual', addressing parental issues in the way that they would regularly do. About two thirds received outpatient services and approximately one third received inpatient care or residential supports. There were no differences between the intervention and the control groups in the mental health disciplines of their involved providers. For 40% of the participants, care was provided by nurses and social workers; another 40% received treatment from both psychiatrists and nurses or social workers. In a few cases, a psychologist was involved.

Some mental health practitioners of parents in the control group reported providing support on parenting in an intuitive way, based on their own experiences as parents. The PARSS intervention was implemented in addition to services as usual in the intervention group. A recruitment period of one year was planned but, with slow inclusion, was extended with 6 months.

*Procedures*

Data were gathered in structured interviews with parents, their close relatives and their mental health practitioners at enrollment in the study (T0) and 1 year later (T1). Interviews were conducted by researchers and trained students. All participants gave written informed consent for participation. Study procedures were approved by the National Medical Ethics Board for Mental Health Care, Northern Region.

*Measures*

The primary outcome variables were parenting satisfaction and success, empowerment, and quality of life. Parenting as defined in this study includes providing care, having empathy, enjoying recreation and play, setting boundaries and limits with children, and talking with children (Kendall & Bloomfield, 2005). On all these dimensions, significantly more improvement was expected in the intervention group. The process variables included relationship with practitioner, quality of contact, satisfaction with the intervention, and a fidelity interview was conducted with PARSS practitioners. At inclusion patients were also asked to give information about their diagnosis.

*Parenting satisfaction*

Defined as self-efficacy in the parenting role, parenting satisfaction was assessed with the Tool to Measure Parenting Self-Efficacy (TOPSE; Bloomfield & Kendall, 2007), completed by parents. This instrument measures parental competencies through self-report on the subscales of Affection, Play, Empathy, Routines, Control, Boundaries, Pressures, Acceptance, and Learning, using ratings from 0 - "completely disagree" to 10 - "completely agree" on items such as "I am able to show affection toward my child" and "I am able to have fun with my child." The original scale proved reliable ($\alpha$ = .89) and adequate for use in a pre- and posttreatment study (Bloomfield & Kendall, 2007). The TOPSE was translated into Dutch according to the guidelines of the International Test

Commission (Hambleton, 1994) using a "translation back-translation" procedure (Brislin, 1980). The translated version had reliability equivalent to the original for the total scale ($\alpha$ = .93) and for all but one subscale ($\alpha$'s from .69 to .84). In our sample the Pressure subscale proved unreliable ($\alpha$ = .36), possibly because of some negatively stated items. This subscale was left out of the analysis.

In an earlier study (Van der Ende, et al., 2010) a majority of parents with mental illnesses reported feeling challenged by finding a balance between parenting tasks and meeting their own needs, particularly in terms of having enough time and energy. Satisfaction with parenting was closely related to keeping this balance. Also, trust in one's own competency while facilitating or doing things with children was an important issue. In line with these findings, extra emphasis was given to these tasks in the PARSS training and two extra subscales were added to the original TOPSE: "Organizing Activities for Children" ($\alpha$ = .70) with items such as "I can arrange a daily routine for my child" and "Balance between parenting and one's own life" ($\alpha$ = .62) with items such as "There is a good balance between my needs and my parenting." With these subscales added, the reliability for the entire scale was as high as the original version ($\alpha$ = .93).

*Parenting success*

Mental health practitioners and significant members of the parents' networks were asked to rate their perceptions of how successful the parent was in coping with the parental role with the same items used in the TOPSE, reconstructed for use as an objective measure ($\alpha$ = .91).

*Empowerment*

Empowerment has been defined as a process by which people, organizations and communities gain mastery over their affairs (Rappaport, 1987). We included the measure of empowerment under the assumption that parents would also benefit from the intervention in a more global way (i.e., they would feel more empowered in general). To measure this concept, parents completed three subscales of the Psychological Empowerment Scale (PES; Akey Marquis, & Ross, 2000, Dutch translation by Peter, Jacobs, & Molleman, 2007): (1) attitudes toward control and competence; (2) cognitive evaluation of certain skills and knowledge; and (3) formal and informal participation. Mental health practitioners and family members completed a parallel version regarding participating parents, with items rewritten as an observation scale for these groups.

*Quality of life*

Two quality of life measures were used. A specific health-related measure, the WHOQOL-BREF (WHOQOL Group, 1998) assesses individuals' perceptions of their position in life in the context of their culture and value systems and the effects of disease and health interventions on their quality of life (1998; Dutch version by De Vries & Van Heck, 1997). A more generic measure, the EUROQOL-VAS, is a standardized, nondisease-specific instrument, often added in studies to complement more specific quality of life measures (Brooks, 1996).

*Relationship with practitioner*

Parents completed the Helping Alliance Scale to measure agreement on task orientation in the relationship between practitioner and parent, and to provide global evaluation of the relationship (HAS; Priebe & Gruyters, 1993; Dutch translation by Wiersma in Catty et al., 2000).

*Quality of contact*

Questions were asked of parents to evaluate the relationship between parent and practitioner in terms of agreeableness, significance, access and sincerity. In addition, the total number of contacts between parent and mental health practitioner over the year was tallied.

*Satisfaction with the intervention*

For parents in the PARSS group, an evaluation of the intervention was included in the 1-year interview. Parents were asked whether they reached the goals they set for themselves at the start of the intervention. Both practitioners and family members of those in PARSS were also asked a small number of open-ended questions to evaluate the program and its possible effects.

*Fidelity*

The researcher conducted telephone interviews with practitioners after 1 year to assess the extent to which the PARSS intervention was conducted as intended. The interview included topics such as the extent to which parenting and empowerment were part of the conversation, and whether the balance between attention to children and time for oneself had become part of the support intervention.

*Analyses*

Cronbach's alpha was calculated to test the reliability of the TOPSE translation. Descriptive statistics and percentages were calculated, and $\chi^2$ tests and t-tests were used to describe and compare participants' characteristics. The means and standard deviations of the scores for the outcome variables at baseline (T0) and at 1 year (T1) were calculated. Baseline differences between the two groups were tested using independent t-tests. As the sample was too small to allow for multivariate analyses controlling for these differences, paired t tests were used to test the significance of differences within the groups from pre- to posttest ($p < .05$, one-sided). The SPSS 20.0 statistical software package was used (IBM Corp., 2011). Themes in qualitative responses to open-ended interview items were reviewed and compiled.

*Participants*

A total of 26 parents participated in the study, 11 of whom were in contact with a PARSS-trained mental health practitioner (see Table 1). All participants had an Axis 1 and/or an Axis 2 diagnosis and were in care for a duration of at least three years. Information from the interviews with parents and practitioners (nurses or social workers) showed that from this group four parents completed the program and three were still working on it: about halfway through the program after 1 year. Four parents did end their participation beforehand: two had ended their contact with the mental health organization and two were working with their practitioners on more acute issues at the time of the interview, such as the death of a family member, divorce or the need to move to another house.

**Table 1. Characteristics of participants in PARSS and control groups (N=26)**

| | PARSS-group N=11 | Control group N=15 | $\chi^2$ test on categories |
|---|---|---|---|
| *Age* | | | |
| a. 21–30 years | 5 (46%) | 2 (13%) | |
| b. 31–40 years | 4 (36%) | 4 (27%) | a vs. b+c |
| c. 41–52 years | 2 (18%) | 9 (60%) | $\chi^2$=5.1 df=, p<.05 |
| *Gender* Female | 10 (91%) | 10 (67%) | $\chi^2$=2.1 df=1, p=.20 |
| *Marital status* | | | |
| a. Married/in a relationship | - | 5 (33%) | |
| b. Divorced/widowed | 4 (36%) | 6 (40%) | a +b vs. c |
| Unmarried | 7 (64%) | 4 (27%) | $\chi^2$=3.4 df=1, p=.11 |
| *Living situation* | | | |
| Together with partner | 0 (-) | 5 (33%) | |
| Not with partner | 11 (100%) | 10 (67%) | $\chi^2$= 6.5 df=1, p<.05 |
| *Living arrangement* Independent | 7 (64%) | 10 (67%) | |
| *Psychiatric diagnosis* | | | |
| a. Mood or anxiety disorder | 4 (36%) | 9 (60%) | |
| b. Psychotic disorder | 1 (9%) | 1 (7%) | |
| c. Addiction/Personality disorder | 5 (45%) | 4 (26%) | a +b vs. c+d |
| d. Other | 1 (8%) | 1 (7%) | $\chi^2$= .82 df=1, p=.36 |
| *Duration of illness* | | | |
| 3–10 years | 6 (55%) | 8 (62%) | |
| > 11 years | 5 (45%) | 5 (38%) | $\chi^2$=2.7 df=1, p=.67 |
| *Highest education* | | | |
| a. University/college | - | 1 (7%) | |
| b. High school/ middle school | 3 (27%) | 8 (53%) | a +b vs. c |
| c. Elementary school/basic education | 8 (72%) | 6 (40%) | $\chi^2$=2,9 df=3, p=.40 |
| *Employment or other regular daytime activities* | 4 (36) | 7 (47) | $\chi^2$=.27 df=1, p=.70 |
| *Number of children* | | | |
| 1 | 6 (55%) | 3 (20%) | |
| 2–4 | 5 (45%) | 12 (80%) | $\chi^2$= 2.1 df=1, p>.23 |
| *Gender of youngest child* Male | 8 (73%) | 9 (69%) | |
| *Age of youngest child* | | | |
| a. >5 years | 7 (64%) | 7 (46%) | |
| b. 6–11 years | 4 (36%) | 5 (33%) | a vs. b+c |
| c. >12 years | - | 3 (20%) | $\chi^2$= .74df=2, p= .39 |
| *Legally responsible for the child* | | | |
| a. Participating parent | 7 (64%) | 3 (20%) | |
| b.… and partner | 1 (9%) | 7 (47%) | |
| c.… and foster parent | 2 (18%) | 1 (7%) | a +b+c vs. d |
| d. Other than participating parent | 1 (9%) | 4 (26%) | $\chi^2$= 2.1 df=1 p=.19 |
| *Average number of contacts with mental health practitioner* | 24.0 SD= 4.2 | 49.5, SD=43.3 | t-test = -2.2 p<.05 |

Comparing the characteristics of participants in both groups baseline differences were found. Both groups featured a greater number of women compared with men. In the PARRS group there are significantly more parents under 30 years old and more over 40 compared to the control group. ($p < .05$). Only a few participants were married or in a relationship, with significantly more parents living without partners in the PARSS group ($p < .05$). In this group, level of education is lower and a greater number of families with one child are found but these differences did not reach significance. There were no differences where legal responsibility for the children was concerned. At T1 the control group had received significantly more contacts with mental health workers than the experimental group ($p < 0.05$).

Parents in both groups met criteria for serious and disabling mental illnesses. Participants reported their primary mental health diagnoses based on the *DSM–IV* (American Psychiatric Association, 2000) classification as assigned by the clinician involved. The most common diagnoses reported were mood or anxiety disorders, personality disorders or addiction. Although many reported illness durations between 3 and 10 years, considerable percentages in both groups had lived with mental illnesses for 11 years or more. Most participants reported serious problems in more than one life domain (e.g., independent living, working, social contacts and parenting). Fewer than half, for example, were employed or had regular activities outside the home.

The characteristics of participants in both groups were similar. More women than men participated in the two groups. Fewer people over 40 years of age were found in the intervention group compared with the control group. Only a few study participants were married or in a relationship, with significantly more parents living without partners in the PARSS group. This was the only difference between groups reaching statistical significance. A greater number of families with one child were found in the PARSS group. Among the children in both groups, over two thirds were boys. Comparable percentages of participating parents and their partners were legally responsible for their children.

# RESULTS

## Primary Outcomes

*Parents' reports*

Parenting satisfaction, as reported by parents via the TOPSE, increased between T0 and T1 in the PARSS group, whereas the mean scores of the parents in the control group remained almost the same over the year (see Table 2). However, this difference between groups did not reach statistical significance. The relatively large standard deviations indicate variation among participants. Examination of individual data revealed that half of all PARSS participants showed an increase in parenting satisfaction, whereas the other half were less satisfied after a year.

Empowerment as reported by parents on the PES was stable over the year in both groups. Quality of life as measured by the EUROQOL-VAS did improve, showing a significantly larger increase in the PARSS group in comparison with the control group. Parents' reports on the second quality of life measure, the WHOQOL-BREF, did not indicate any differences between groups.

**Table 2. Differences between baseline and results after one year for the intervention and control group**

| | PARRS Group | | | | Control Group | | | | Comparison |
|---|---|---|---|---|---|---|---|---|---|
| | T0 Mean (SD) | T1 Mean (SD) | Diff. Mean (SD) | n | T0 Mean (SD) | T1 Mean (SD) | Diff. Mean (SD) | n | Baseline t-test |
| *Parents as source* | | | | | | | | | |
| Satisfaction: TOPSE | 371.2 (44.6) | 383.8 (39.6) | 12.6 (38.5) | 11 | 348.1 (52.8) | 346.0 (49.3) | –2.1 (48.2) | 15 | t=1.1 df=24 p=.24 |
| Empowerment: PES | 79.1 (10.8) | 80.4 (9.4) | 1.3 (12.0) | 11 | 67.3 (14.4) | 68.9 (14.4) | 1.6 (11.9) | 15 | t=.09 df=24 p<.05 |
| Quality of Life: EUROQOL-VAS | 5.2 (.6) | 5.9 (.6) | .7* (3.1) | 11 | 7.0 (1.4) | 6.7 (.2) | –.3 (1.6) | 15 | t=-2.3 df=24 p<.05 |
| Quality of life: WHOQOL-BREF | .6 (.3) | .7 (.3) | .1 (.3) | 11 | .7 (.2) | .7 (.1) | .0 (.2) | 15 | t=-1.3 df=24 p=.08 |
| Relationship with practitioner: HAS | 35.4 (8.5) | 33.0 (13.2) | –2.4 (13.9) | 10 | 34.5 (6.2) | 35.5 (6.1) | 1.0 (9.1) | 15 | t=.30 df=24 p=.76 |
| Quality of contact | 23.1 (2.7) | 22.1 (3.0) | –1.0 (2.8) | 11 | 21.3 (4.3) | 22.6 (2.8) | 1.3 (4.7) | 15 | t=1.2 df=24 P=.13 |
| *Mental health practitioners and next of kin as source* | | | | | | | | | |
| Success: TOPSE | 329.8 (40.4) | 329.3 (51.2) | .5 (40.4) | 18 | 309.7 (78.9) | 307.0 (73.2) | –1.7 (51.4) | 20 | t=1.3 df=34 p<.01 |
| Empowerment: PES | 75.9 (12.3) | 70.1 (17.3) | –5.8 (14.7) | 21 | 64.0 (17.2) | 68.0 (18.1) | 4.0 (14.5) | 20 | t=2.7 df=36 p=.13 |

*Significant difference between baseline and outcome after one year, p<.05 (tested one-sided)

At baseline significant differences between the groups in the main outcome measures are also apparent, with lower mean scores on success with parenting ($p=<.05$) and higher scores on empowerment ($p<.05$) for the experimental group. Parents in this group also rated themselves to be less successful in parenting ($p<.05$) than parents in the control group but were rated as more successful in this regard by others ($p<.05$).

At 1 year, practitioners' and family members' reports of parenting success were stable in the intervention group, whereas in the control group a slight improvement could be seen. With regard to empowerment, the scores for those reflecting on parents in the PARSS group started higher than for those regarding parents in the control group, but they decreased after 1 year, whereas the scores increased for the control group. Upon closer inspection, the seven parents in the PARSS group who did not complete the program had significantly lower empowerment scores as reported by practitioners and family members than reported for the four parents who completed the intervention.

## The Intervention Process

*Relationship with practitioner and quality of contact*

There were no significant differences between the parent-reported scores at T0 and T1 regarding relationship with the mental health practitioner as measured by the HAS scores, nor in the scores on quality of contact between parent and mental health practitioner. This was the case in both the intervention and the control groups.

*Satisfaction with the intervention*

In the PARSS group, both parents and mental health practitioners were positive about the program. All the parents felt they received the support that they needed for parenting. They were more aware of their part in parenting, and had learned how to care for their children within their abilities. They had gained more insight into overcoming the problems they faced. Some of the parents expressed this as follows: "The program helped me to get a framework of support and means for parenting," "[It was] instructive; I made progress in my role as a mother," and "Nice and clear—it gives structure." When asked whether they had reached the goals chosen at the start of the program, 9 out of 11 PARSS parents confirmed this was the case. Examples of their goals included: "being more confident with the kids," "having more authority," "being free of the always claiming child," "giving structure" and "improving the relationship."

In the 10 telephone interviews with the mental health practitioners from the PARSS group, all were positive about working with the intervention. They responded: "If the parent is open for it, the program is good. It is a professional program"; "It is very positive and applies to certain parents; it is not threatening"; "It makes you alert to what works with the parent." One case manager stated he had found greater fulfillment in his contacts with a father he was counseling. PARSS gave him more structure in his work and he could see progress being made in parenting.

### Fidelity

Ten of the 11 PARSS mental health practitioners were interviewed regarding intervention fidelity. One of the practitioners could not be reached. All practitioners reported working with parents on the development of parenting skills, and on achieving a balance between parenting and leisure activities. As stated above however, only four of these10 practitioners completed the entire PARSS intervention with the parent. The others completed only the first workbook, with a focus on assessment, and did not implement the second part of the intervention, which focuses on strengthening or taking back the parental role.

## Discussion

In this pilot effect study, the outcomes of the Parenting with Success and Satisfaction (PARSS) program pre- and post- intervention outcome measures were available for 11 participants and corresponded to a one-year period. The outcomes were based on information provided by parents, professionals and persons in the network of the parents. Changes in satisfaction with parenting and in the empowerment and quality of life were based on self-reported information. To learn the specific effects of the program, this self-reported information was compared with recorded changes in these measures for 15 parents who were not enrolled in the program, but who had discussed parental issues with their caseworker. All 26 parents in the study received long-term outpatient care from a mental health center.

*Primary Outcomes*

PARSS was developed to enhance the possibilities of parenting for those living with severe mental illnesses. In the PARSS group, parenting satisfaction increased (i.e., showed a positive trend), but did not significantly differ from the control group. Self-reported quality of life changed on one of the two measures over the year in both groups, with a significantly greater change in a positive direction for the PARSS group compared with the control group.

There were no significant changes in either group in parenting success as reported by mental health practitioners and family members. Empowerment as reported by parents did not show change. Practitioners and family members reported a greater change in empowerment for the control group parents, with no such change reported for the PARSS group.

The finding that, according to mental health practitioners and family members, parents in the control group showed an increase in empowerment, whereas the empowerment of PARSS parents decreased, is puzzling. Perhaps parents in the PARSS group, perceived as less empowered by their practitioners and family members, had become more dependent on these professionals. Parents in the control group gained more independence from their practitioners' and family members' perspectives. Further

inspection of the PARSS group data made clear that the seven parents who did not finish the intervention had significantly lower scores than those who did complete it. It may be that empowerment is more strongly supported in later phases of the intervention.

Wary of the risk of over interpretation, we also suggest consideration of the ways practitioners can support parents to stimulate empowerment. If the tendency to dictate to parents about children's upbringing overshadows a more rehabilitation-oriented, empowering approach, the development of a sense of empowerment may be impeded by a lack of focus on the parent's own sense of control or independence. Practitioners must find a balance between, on the one hand, stimulating the development of and leaving responsibility to the parent and, on the other hand, taking responsibility for the situation where children are concerned, particularly if safety issues arise. However, when practitioners can see themselves as resources, with the parent in the leading role, some parental dependency on professional and natural resources can be fruitful. As Anthony and Farkas (2012, p. 41) state: "From a rehabilitation perspective, dependency is not a dirty word. Dependence on people, places, activities or things is a normal state of affairs." When measuring empowerment one should note that, in the first phase of the intervention, parents may be more dependent on mental health practitioners. An increase in parents' empowerment may potentially be evident in later phases or at full completion of the intervention. Further studies are needed to discover whether this pattern is replicated in comparable situations.

All in all, there is some evidence that PARSS fills a gap in supporting parents with serious mental illnesses and psychiatric disabilities; outcome data provide evidence of positive trends. The instruments in this study seemed to be useful. Because the intervention is new and the pilot sample is small, more research with larger samples is necessary to fully assess outcomes and reach statistical significance. Given that the data from this small sample show great individual variability, qualitative and process-focused studies could provide more insight into who benefits from the program and why. Parents, mental health practitioners and family members evaluated PARSS as a useful approach, especially considering that, until now, no such intervention has been available.

*The Intervention Process*

Process and fidelity measures provided evidence that PARSS was fully implemented as intended only in some cases. Practitioners implemented PARSS with a small number of parents; they subsequently completed only portions of the intervention. The impression, from interviews, was that parents and practitioners began the intervention in a systematic way, but then priority shifted to other serious problems as they emerged. PARSS participants' attention may have moved on to another issue or topic, and away from a specific focus on parenting.

The intervention was implemented in four mental health organizations or agencies, whose practitioners were trained in PARSS. The integrity and sustainability of the

intervention was left to the organizations. Practitioners acknowledged they did not "stick" to the intervention all the time. More attention could have been paid to the implementation process by obtaining clear commitment from organization or agency management to implement the intervention, and by having one person per organization as the PARSS liaison.

Nonetheless, the outcomes indicate that a one-year program is too long for some of these parents. Only four of the ten parents completed the entire program. Evaluations with the workers are not reported, but were used to further develop the program and the training; we learned that workers should be aware of the influence of the professional context in which support is given to parents. Stimulating empowerment by a mental health professional was found to not always yield the desired effect in a situation in which parents are dependent on the services and support of this same mental health professional.

In retrospect, this study was conducted and outcomes were measured during a developmental phase when PARSS had not been fully implemented. This provided useful data, from an intervention development perspective, to inform further refinement and successful implementation in the future (Patton, 2011). Interventions developed and testing in community settings may be more generalizable and sustainable as they are brought to scale (Hoagwood, Burns, & Weisz, 2002).

## Strengths and Limitations

The strength of the PARSS intervention is that it explicitly focuses on supporting parenting, which is often a neglected domain in mental health services. Another strength is that the PARSS approach is built on the evidence-based practice of psychiatric rehabilitation (Swildens et al., 2011), and informed by theory and practice supported in the literature. PARSS provides clear goals and a structure for working together with parents. The subjective reports of participants indicate that PARSS is useful in terms of improving the balance of taking time for one's own life and meeting parenting demands. Mental health practitioners report improvements in their way of working. Our findings regarding the PARSS implementation process provide insight into recommendations for the future.

Attention must be paid to ensuring implementation of the intervention with fidelity to the model. Ongoing supervision groups and training booster sessions may be helpful to practitioners. A more specific fidelity measure should be developed. Attending to individual differences and variability among parents, and tailoring the intervention and evaluation in light of this variability should help to adapt PARSS to match participants' needs better and to demonstrate significant impact.

This pilot effect study has a limited number of participants (26). In the end 10 trained workers of the potentially 100 workers were able to refer patients, who actually participated in the study. For the control group, recruitment was done by mental health workers in four teams from other comparable mental health organizations. It is hard to

give a sufficient answer as to why at the end only 11 patients could be included. Some of the possible reasons are: 1) practical: to make a good start, workers had to know about the wish of a parent to work on goals referring to their parental role but this could not already have been part of the support already given 2) on the parents side there could have been reluctance to follow a one-years-program in parenting and being part of a study, 3) on the side of the professionals it could be discomforting to be part of an effectiveness study for such a new intervention. Possibly if there had been a financial compensation, recruitment would have been somewhat easier (cf Wansink et al. 2014). However we do think that the stigma around parenting with SMI and the fear of parents to explicitly share their worries and difficulties with professionals could be a reason that parents hesitated to enter the study. The fact that not only information was asked from parents and workers but also from a third party, for instance a family member of neighbor, was possibly an extra threshold to consent. Unfortunately there was no information on parents who declined participation so no non-response analysis could be made.

Although no formal criteria were used to only include parents with severe mental illness, the choice of recruiting via professionals working in long term care did result in a sample of parents who met at least two of the SMI criteria (a psychiatric diagnosis and dependent of care for a period longer than two years).

In this pilot study, the outcomes of the Parenting with Success and Satisfaction (PARSS) program pre- and post- intervention outcome measures were available for 11 participants and corresponded to a one-year period. The outcomes were based on information provided by parents, professionals and persons in the network of the parents. Changes in satisfaction with parenting and in the empowerment and quality of life were based on self-reported information. To learn the specific effects of the program, this self-reported information was compared with recorded changes in these measures for 15 parents who were not enrolled in the program, but who had discussed parental issues with their caseworker. All 26 parents in the study received long-term outpatient care from a mental health center

A significant difference in the change of the quality of life is found between the intervention group and the control group, the small sample size limits statistical impact. Several characteristics point to more disabilities among the participants in the experimental group in comparison to the control group e.g. unmarried, low education level, not living with a partner, and on the other hand a higher score on the empowerments scale. As for now it is not clear how this could have influenced the outcomes as, with these small numbers, no predictor analyses can be done. Such analyses could have shed a light on the influence of certain parent (or child or worker) characteristics that influence the outcomes, success and satisfaction with parenting. Within this information lacking two different hypotheses could be formulated. First, possibly for those parents with more severe problems the program leads to a more

significant ‘growth’ i.e. increase in not only success and satisfaction where parenting is concerned but also an increase of empowerment and quality of life. On the other hand it could also be that this group has a harder time to develop their parental role and profits less from the intervention.

This pilot research indicates that the PARRS program can be used by mental health professionals. The results are mixed. Parenting satisfaction increased after one year for the PARSS group, not for the control group, and a significant difference in the change of the quality of life was found between the intervention group and the control group. The small sample size limits identifying additional statistical effects. The study is intended to inform future studies.As this was a pilot study, larger controlled studies are needed, with special attention to tailoring the PARSS intervention and enhancing fidelity. Researchers in the Netherlands as well as in other countries are hampered by the challenges in securing funding for both services and research with numbers of participants great enough to build the evidence base in traditional ways (e.g., large-scale, randomized control trials). In addition, the issues of empowerment and consumer choice in psychiatric rehabilitation may take priority over the random assignment of participants to conditions. These circumstances suggest the importance of collaboration within and across national boundaries to build the evidence base in creative ways on behalf of parents living with mental illness and their families.

## Conclusions and Implications for Practice

Although the first experiences with the PARSS program were mixed, the PARSS intervention has the potential to function as a useful tool in supporting parents living with serious mental illnesses. As a guided, self-help intervention, it fills an important gap in available psychiatric rehabilitation resources for parents and practitioners. Important lessons were learned in this study regarding variability among parents and the implementation process.

# CHAPTER 6

## GENERAL DISCUSSION

The starting point for this thesis was the question how people can be supported when they are challenged by both mental health problems and parental tasks. Several research designs were used in this thesis to gather knowledge about the recovery strategies of these parents, their needs for support, the professional support available and the development and evaluation of a new rehabilitation program aimed at the parental role. In this final chapter a conclusion is formulated based on both the literature on parents with mental health problems and on the new information derived from the five different studies described in this thesis encompassing the experiences and evaluations of 100 parents and 154 professionals of health organizations. In this concluding chapter four sections can be distinguished.

First the epidemiological data about this group will be discussed followed by an overview of what we know and understand of the barriers and problems parents with mental health problems face when raising children, their needs for support and also their own successful ways to cope with this. An attempt is made to draw a *needs-barriers-motivation-strategies-goals model* that helps to integrate the described findings and facilitates understanding of the manner and content of support that could be offered. The second section focuses on this support, the role of professionals at this moment and a first indication of the effects of the developed program "Parenting with Success and Satisfaction". Reflecting on these results of other recent studies on family interventions an advice is formulated on possible fruitful ways of practice to provide for children, parents and professionals. In the third section recent developments in supported parenting and recovery are described as are suggestions for further research. A more general conclusion forms the fourth and last part of this chapter.

## Parents with mental health problems; an overview

To get an indication of how many people with mental health problems are also parents no direct sources are available. It is not common practice for health organization to registers the children of people with mental health problems and no recent survey data are available. Only estimations based on surveys and national population data on mental illness are used to estimate the number of parents with mental illness. Comparing data from different sources we concluded that of all people with mental health problems in 2009 almost half (48.1%) had one or more children under the age of 18 and that the same holds true for people with severe mental illness making the total number of parents with SMI almost 68.000 (chapter 2 of this thesis). Since then some more recent data are available. The client registration data from the University Center of Psychiatry (UCP), Groningen, the Netherlands, indicates that 37% (N=590) of individuals who entered the

3 Recent data analyzed by Ellen Visser (Rob Giel research Center, RGOc) for client population UPC in 2015, Groningen

clinic in the year 2015 had children. This percentage is lower than the 48.1% based on Nemesis-2, though could be influenced by the specific population demographics of this center. In recent years, Delespaul & Consensus group (2013) developed the following new criteria for SMI: a psychiatric disorder requiring care (not in symptomatic remission); coincides with severe disabilities in social behavior (not in functional remission); the cause and the consequence are a psychiatric disturbance that is not transient, i.e., lasts at least several years; and the coordinated care of professional workers in networks is used to implement the individual care scheme. Based on these criteria, they estimated the percentage of people with SMI in the Dutch population between 18 and 65 years to be 1.6%, whereas we used 1.9%. Based on the criteria of Delespaul et al, the estimated number of parents with SMI would be 57,000 instead of 68.000.

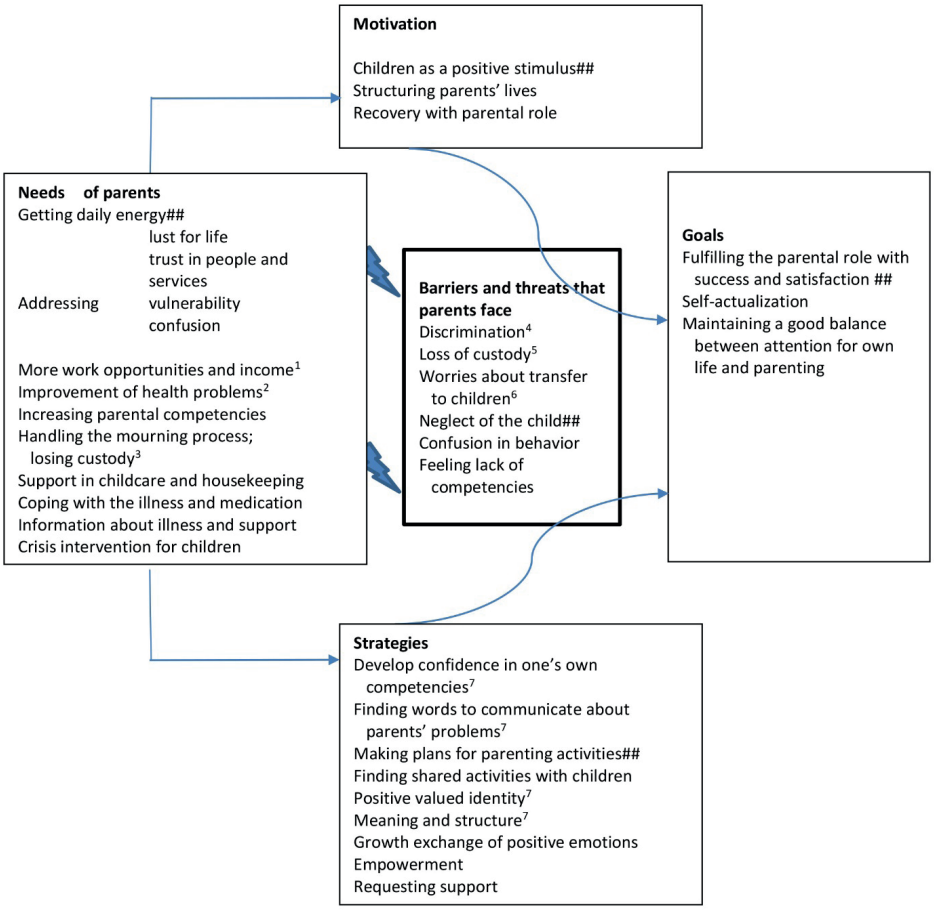
In the light of the international literature, our figures can also be debated. In the US, higher percentages are reported. Nicholson, Biebel, Williams & Katz-Leavy (2004) found that 67–75% of patients with SMI were parents, which is approximately 20 percentage points higher than the 48% that we estimated based on figures from the Netherlands. In Australia, again a lower percentage is found; 25–28% of patients who are parents (Howe et al. 2012). Whether these differences are due to the definitions of mental illness that are used in the studies, to using different types of measurements is not clear. Cultural differences, for instance the mean age of the parents when the first child is born, availability of birth control devices or differences in the health or social security system could also account of these differences. As for now, the conclusion seems legitimate that in the different mental health systems there is indeed a relatively large group of people, one or two out of every four people with SMI, who also face parental tasks.

Our qualitative exploratory study emphasized the need for professionals to address parent-child interactions. The interviews showed that the combination of coping with their mental health problems and caring for children makes parents vulnerable. On the other hand, the birth and raising of a child were also experienced as positive stimuli, giving new meaning to the lives of these parents. Dedication to this significant life role provided a focus; parents developed strengths and skills as they found a balance between attending to their own lives and caring for their children. Parenting prompts them also to find adequate sources of social support. Parents described many sources for support, organized and substantiated in very individualized ways from different, informal and professional sources. It can however be hard to request support to help raising their children for parents especially when they feel this as failing; parents might be anxious to have a risk of losing custody of the child. In an adequate (mental health) care system professionals should be aware of these incongruences and thus provide constructive support for those who seek parenting support whilst also taking the welfare of the children involved into account.

## Needs, barriers, motivation and strategies for good parenting

To comprehend both opportunities and constraints that parents with mental health problems face and to discover the relationship between several concepts in parenting and mental health problems we constructed a model of *needs, barriers, motivation, strategies and goals*. This is meant to clarify the process that is based on parental strategies of people with mental illness to fulfill a parental role with success and satisfaction. The model starts with parental needs. Next are barriers that might obstruct the achievement of good parental goals. Motivated by stimuli from their families and/or strategies developed on the way, makes it possible to pass by the barriers. Final goals such as a satisfying and parental role can be executed. Figure 1 gives an explanation of this model with in the boxes the input from both recent literature (among others Coverdale & Aruffo, 1989; Hosman et al. 2009; Carpenter-Song and Nicholson, 2012; Jeffery et al. 2013) and the first part of this thesis (chapters 2-3). The two arrows that are drawn from needs to strategy and from strategy to goal were intended to show how as a consequence of a certain need parents develop new strategies in order to reach these goals. The goals as such are based on motivations explicated in the top of the model.

**Figure 1 Needs, Barriers, Motivations and Strategies and Goals to fulfill the parental role by people with mental illness**




##No reference numbers means item is found in chapter 2-4
1 Mowbray et al. 2001
2 Miller ,1996
3 Haans et al, 2004; Zeitz, 1995
4 Jeffery et al. 2013
5 Coverdale & Aruffo, 1989
6 Hosman et al. 2009
7 Carpenter-Song and Nicholson, 2012

***Needs -*** The mental health problems themselves, like mood, anxieties and stress, severely influence one's capacity to deal with the day to day tasks around and interaction with the children (chapter 1). Extra general health needs leading to fatigue and loss of vitality also play a role and need to be addressed by the parent and the one who supports him or her (Miller, 1996). Medication, especially psychotropic drugs can influence parental abilities (Howard & Kumar, 2001) and thus in those situations where the child's custody is an issue there are worries, possible reluctance to be open about problems and a need for support. And, in cases with the loss of a child towards a foster family or ex-partner while handling the mourning process, there needs to be adequate support for a parent (Haans et al. 2004; Zeitz, 1995). In the needs assessment described in chapter 12, apart from these large problems, parents also expressed more specific and concrete needs for support like for instance help with practicing ways of entering into a conversation with the child, advice on how to deal with the child's behavior and demands, and also help to nurture in a way satisfying for both child and parent. From a more practical angle, some expressed the need, for legal assistance or help with arranging support from peers.

Occasionally, the needs are expressed directly. In other cases, parents are silent about their needs for the parental role (Mowbray et al. 2014). For example a parent can be reluctant to contact teachers at their child's school. If not supported to overcome this threshold, problems could arise in the communication and a potential good source for further support is missed.

***Barriers -*** It is important to note that whereas all interviewed parents from the study in chapter 3 felt the negative effects of their mental health problems on parenting, there was some reluctance to share this with professionals and sometimes also within the informal network of support. Not talking about problems in the parental role can be caused by anticipated discrimination (Jeffery et al. 2013), fear of the loss of custody (Coverdale & Aruffo, 1989) of the children and neglect by the parents (Van Santvoort et al. 2013). Also fear of transferring one's own problems to children by heredity, or the transfer of the feelings and behavior of parents can form barriers (Hosman et al. 2009).

***Motivation -*** One way to work on these problems is to use one's motivation and also strength as a parent. In our studies, we found that parents are eager and motivated when raising their children (see chapter 3). From this motivation parents' resilience is strengthened. Parents experience that their life is structured by their parenting tasks and that children provide a positive stimulus that helps them to partly overcome issues related to their mental health problems like a single mother with a two-year-old child said in Chapter 3:

> *Motherhood gives me a lot of satisfaction and yes, since I am a mother, I have stood firmly on my feet. It has changed me a lot. I have to take responsibility that already starts after waking up. You have to be there all day; you cannot leave your child.*

***Strategies -*** Parents and mental health professionals can use the described strategies (chapter 3) for their goals in developing the parental role. Professionals can coach parents while using the strategies. In supporting the further development of the parental role, professionals and parents can focus on increasing competencies or skills and on providing environmental support. Despite their mental health problems, the interviewed parents in our study felt capable of bringing up their children. They invested in shared activities with their children for the purpose of being together and experienced that having children contributed to meaning and structure in live and to a positive valued identity.

***Goals -*** Fulfilling the parental role with success and satisfaction forms the goal of the indicated needs powered by motivation and strategies (see chapters 2 and 5). This means for example adequate expression of empathy and emotions to the children and the setting of boundaries and control. Also self-actualization and maintaining a good balance between attention for one's own life and parenting are important goals in parenting.

The model is designed to be a framework to help structure the different notions in the literature, the experiences of parents shared with us during the study and the results of the presented studies. This model was used as a tool to clarify how findings are related and used thus, helped to illuminate the various positive strategies that people with a mental illness use to fulfill a parental role successfully and satisfactorily.

## Support of the parental role

*Professional support*

Parents' needs and goals are studied in the first chapter of the thesis. Next we have studied what support to the parental role is offered by different health organizations. A cross-sectional internet study with 128 participants showed differences in attitude and practice between mental health organizations and general hospitals where support for parenting is concerned. The question whether hospital staff pays attention to the needs of hospitalized patients in their parenting tasks and whether this capability differs between general hospitals and mental health facilities was central to this study. It occurred that twice as many workers in general hospitals than in mental health organizations found sufficient opportunity to provide support to the parental role.

Another attitude and less constraint are found in those mental health organizations where workers are trained in supported parenting. All in all more training and development of competencies in supporting parents, with a recovery and psychiatric rehabilitation point of view, seem to be needed. However one could argue that supported parenting is not part of the care or treatment in mental health organizations and belongs more to Child- and Youth care or Welfare organizations. Still in every health organization it is relevant to think about and work on social roles of the patient and include family members in some parts of the treatment.

Thinking in terms of families, mental health organizations can do a lot with parents and their children. Van Santvoort et al. (2014), who studied the effect of a preventive intervention targeted at the children of parents in mental health care, found that children do benefit from such an approach but that these effects could be extended when the parents are involved. Elements of the PARSS program could be used to set up such an intervention that can positively strengthen parents in their interaction with the children.

This does not have to be the sole responsibility of the specialized mental health organizations though. Primary care professionals and professionals in programs promoting mental health or preventing mental illness in the general public can also provide these kinds of support. Increasing awareness of need for support of both parents and children and adoption of such strategies could reduce the burden of mental illness in individuals and families and so on society as whole (Enns et al. 2016). In our qualitative study (chapter 3) we found that social acceptance and knowledge of mental health problems are very important as anticipated stigma constrains parents to ask for help. Van Santvoort et al (2014) also emphasis the negative influence stigma has on children and stress the importance of early interventions, psycho-education and the use of low threshold sources of information and exchange. More research is however needed to clearly understand the benefits of these preventive measures (Fernandez et al. 2016).

Some professionals show reticence to act, in situations of parental violence and neglect. They find it difficult to coach and show solidarity with parents in combination with staying alert to the safety of the children. Training in how to address these situations is needed to overcome the risk, on the one hand, that professionals brush aside a situation that is dangerous to the child or, on the other hand, that overly rigorous solutions will be taken such as bringing children to another location by force and removing parental custody. In many ways professionals can help prevent families from being derailed. Not only should professionals be more family-directed in their contact with those in care, but they should also help stabilize and built social networks around parents and their children to maintain the families in the community and keep the children and biological parents together. The social networks approach seems to achieve the best result if a strength model is used in which the possibilities and strengths of parents and children are emphasized and in which parents are enabled to obtain or maintain a grip on their own life (Reupert & Maybery, 2014). An integration between informal support and professionals, who will coach and support the informal network, is needed.

Supported parenting integrated with supporting children in a family model makes a good change for the future (Wansink et al. 2014). Recovery and psychiatric rehabilitation are valuable starting points for family support. They have in common that the aim is to involve the least necessary professional help. The realization that informal and professional care needs to be organized within the communities points to a more community-integrated care. Professional health workers can move more to a position of organizing care within a patient's own network.

*Evaluation of a new program to support parents*

We examined the initial experiences with and the effect of a newly developed psychiatric rehabilitation intervention for parents called Parenting with Success and Satisfaction (PARSS). This intervention, inspired by psychiatric rehabilitation (Farkas & Anthony, 1991) explicitly focuses on supporting parenting, which is as described before often a neglected domain in mental health services. PARSS, explicitly targets parental emotional regulation. Because people learn and develop competencies and strategies for the parental role by this program it is not dependent on the specific psychiatric diagnosis of these parents. Parents with any diagnosis can learn competencies for their parental role. Such targeting on competencies is a useful strategy in developing interventions for families (Maliken & Katz, 2013). PARSS is aimed at improving the balance of taking time for one's own life and meeting parenting demands. This means it also targets possibilities and parental strategies.

In a quasi-experimental pilot study, PARSS was evaluated by parents (N=26), by health professionals and by close family members (including partners). The program was shown to be effective, albeit results were mixed. Parenting satisfaction increased after one year for the PARSS group but not for the control group. And, although a significant difference in the change of the quality of life is found between the intervention group and the control group, the small sample size limits further statistical effect. On the other hand process measures showed that, although PARSS was not always implemented as intended, both parents, professionals and informal sources of support like family members, expressed satisfaction with the intervention and its results. The parental role was not only developed by the steps in the program but the workers also served as good role models for parenting.

A logical follow-up of this study would be to perform a Randomized Controlled Trial (RCT), with the instruments that are used in this pilot study. However, considerable attention should then be given to the inclusion procedure, given the problems encountered in including participants the pilot study. The pilot-study however seems to have the potential to function as a useful tool for supporting an international standard measurement for evaluation of supported parenting. Although limited because of its small sample size and quasi-experimental design, it (this pilot-study) gives a first indication of the usefulness of the program the adequacy of the evaluation instruments used and potential changes in regard to parental role functioning.

If this intervention has proven to be effective, workers trained in practicing supported parenting can contribute to strengthening the skills and capabilities of parents with mental health problems and thereby decreasing their vulnerability. As for now, PARSS was implemented in a national organization for training in psychiatric rehabilitation, "Stichting Rehabilitatie '92". They provided about 12 in-company trainings in mental health organizations. At least three large mental health organizations offer this program to clients on their website.

## Limitations of the studies

The presented studies are only a part of the body of knowledge in the field of Families where a parent has a mental illness (FaPMI).

In our study the focus lies on parents with severe mental health problems. However not in all studies strict criteria were used to include only this group because of practical reasons for instance when data were not available to do this in a very strict sense a the most practical selection, people in long term care, was used. For the epidemiological study not only current problems and contact in the mental health system should have been used but also the specific psychiatric diagnoses and an indication of functioning should be used to arrive at a better estimation of the SMI population (cf Ruggeri, 2000). Furthermore, population studies like NEMESIS-2 underrepresents SMI. So the percentage of patients with SMI, the number of people having children might be higher

The strong emphasis on the positive aspects of parenting in the study of strategies (Chapter 3) could be a consequence of the fact that we recruited people for interviews who were parenting actively and successfully, and who were willing to talk about and could express themselves well with regard to parenting. This was an important research decision, however, as our goal was to shed light on strategies leading to successful outcomes for parents and children. However, although we did not make a distinction between mental health problems and severe mental illness in the recruitment, the characteristics of the group show that a lot of participants indeed could be seen as members of the group with severe mental illness.

The study on professionals' opinions about supported parenting (Chapter 4) through a web-based internet questionnaire gave possibility of bias. To discover similarities and differences between professionals in mental health organizations and general hospitals in regard to support to parents, we chose to conduct an online explorative study. The extent to which these results can be generalized to professionals in other hospitals is unknown. According to. Walker (2013), the online research method is an effective method to collect data. Although information about non-participants is missing, internet-based findings are consistent with findings based on traditional methods.

In the pilot study on the effectiveness of PARSS only a limited number of participants could be included. It is our impression that it was difficult to find people for a parenting program because the subject of supporting and recognizing the parental role of people with mental health problems is challenging. The small sample size limits the statistical impact of the study. The inclusion was done in mental health organizations. Patients were asked what diagnosis they have. This is presented in table 1 in chapter 5. Axis I and Axis 2 diagnosis can be found. The duration of the psychiatric problems is at least over three years.

As this was a pilot, larger controlled studies are needed, with special attention to tailoring the PARSS intervention and enhancing implementation fidelity. For this purpose a more specific fidelity measure for PARSS should be developed.

Nevertheless, the question of how to include a number of parents sufficiently large for an adequately powered RCT (Randomized Control Trial) remains unresolved. One of the possibilities is requesting experts by experience who have children to invite potential participants. Also, if admitted by the ethical committee a gift amount might be stimulating for participation.

The children who are the main subjects of parenting were not interviewed in the pilot study of PARSS. Although possibly of great value, we expected that gathering information from the children at hand, might have led to complicated situations for both children and parents. As children are strongly connected to their parents, they show in a lot of cases a strong solidarity with their parents. At different ages and different times in their lives their answers might be inconsequent. It is also suggested that talking with an interviewer about mental health subjects might disturb children (Riebschleger, 2007). Extra prudence is needed in case of involving children of parents with mental illness in a study.

## Implications for practice

*Combined with changes in the Dutch care system*

In the Netherlands there have been two major changes in the health system that are of importance where parents with mental health problems and their children are concerned. As in most European countries, in the Netherlands mental health care is changing from being provided in hospital settings to being provided by teams in the community. In all regions so called Flexible Assertive Community Treatment (Flexible ACT) teams have been installed, following a rehabilitation-oriented clinical case management model for service delivery of the care and treatment of the most severely mentally ill people in the community. In this way social care and support to people are provided near or in their homes (Meinema, 2014; Nugter, Engelsbel, Bähler, Keet, & Remmers van Veldhuizen, 2015). Also in the national action plan 'Crossing the bridge' coordinated by the Dutch National Centre of Expertise "Phrenos" (2014) it is underlined that good treatment, guidance and support should target not only the patient but also his/her immediate circle. The networks for the treatment, guidance and support of people with serious mental health issues should be organized at a regional level with a consultation structure including main providers, client organizations, and funding sources in each of the 43 designated regions in the Netherlands.

In recent years, the care system in the Netherlands has made another change with the transition of the budget and the responsibility for social care, youth care and vocational participation of vulnerable groups from a national level to a local level (the municipalities). Community Support teams (or social care and support teams, Meinema, 2014) in the Netherlands provide social care and support or will do so to people near or in their houses. Forced by changes in the financial system, municipalities started offering suitable care to citizens who are unable to participate fully in society on their own.

Starting points are: at first addressing citizen's own strength, next activating the social network and volunteers and at last the support of the professionals. This is also the line in using and coaching strategies in parenting by people with mental health problems.

*Consequences for education and training programs*

In the literature of personal recovery and in the education programs for experts by experience the parental role seems to be underexposed. It might give a good contribution to use the knowledge of "families where a parent has a mental illness" in these programs.

In addition to support people with mental health problems to achieve their living, working, learning and socializing goals of own preference also their parental role needs support. Psychiatric rehabilitation programs should address this, for many people, most important role.

*Consequences for supported parenting*

If people with mental illness stay in the community and families are not disassembled, there are more opportunities to work with the network as a whole and the resources within, like in the so called-family model as explained in the upcoming paragraph "Family and parental mental illness".

Some services are aimed exclusively at adults, others at children and young people. Combining the work from different viewpoints and different organizations with the starting point to support all family members creates good opportunities for both parents and children.

A better registration of the presence of children, their potential problems and of the parent-child relationship is necessary for adequate control of the provision of care at both the individual level and the macro level.

## Recent developments in supported parenting

*Overview of programs*

In the time span during and after the studies of this thesis, the field of supported parenting expanded in more than one way. This paragraph describes recent developments in the support for the parental role of parents with mental health problems.

PARSS stands in the tradition of parenting programs. For parents in general different programs can be found, for example Triple P (Positive Parenting Program, Sanders et al. 2014). This program provides practical strategies to parents to help them confidently manage their children's behavior and build strong, healthy relationships. If there is a need for these strategies, this program is also relevant for parents with a mental illness. Specific programs are also developed for parents with mental health problems (Wansink et al. 2014; Wenselaar, 2015). This is besides the specialized family therapists who have made treating families their profession in the last decades.

Cook and Mueser (2014) signaled a new generation of recovery-oriented psycho-social rehabilitation services for mothers and fathers. Opportunities for enhanced services for parents are provided in particular by self-help and peer-support programs for parents with lived experience (Hinden et al. 2006; Reupert & Maybery, 2011; Schrank et al. 2015). These programs are recovery-oriented and more aimed at the attitude of the parents than towards the behavior of the children, like for instance Triple P (Sanders et al. 2014). The recovery-oriented programs do not have deficit approaches with an emphasis on problems and pathology. They do not fit parents and children into pre-existing service plans but provide tailor made services.

Apart from these programs, providers of all types of mental health, medical, and social services and school personnel are encouraged to focus on family strength (Reupert & Maybery, 2014). There is growing awareness of how parents living with mental illness can benefit from peer support. Professionals encourage them to share ideas with other parents and to engage in talking about parenting concerns (Hinden et al. 2006; Reupert & Maybery, 2011; Van der Ende et al. 2014). Also experts by experience can play a role in parenting. Courses for experts by experience are advised by the results of this thesis to pay attention to the parental role.

Additionally, new initiatives are worth noting: 'Support families' (www.meeleefgezin.nl), a program in which volunteers support a whole family with mental health problems; 'support parents' (www.steunouder.nl) where volunteers help to care for the children of these parents; 'Mama-cares' (www.mamacares.nl), in which parents with mental health problems are trained to coach peer-group sessions; and "Online support", an internet peer support program for individuals with psychiatric disabilities which was recently developed in the Netherlands (Van der Zanden et. al. 2010); in the US (Kaplan, Solomon, Salzer & Brusilovskiy, 2014) have found positive results after evaluating an online program. Children are able to chat in groups, while a moderator gives sometimes professional advices.

As mentioned earlier, making progress in supported parenting is not reached by supporting an isolated parent but can best be done within the network with various family members. A possible way of organizing this can be found in the recently developed Resource group assertive community treatment (RACT) model, a variation on the Assertive Community Treatment (ACT). RACT is a combination of ACT and the so called 'resource groups' (Nordén, Malm & Norlander, 2012). In RACT the clients, their family members and other next of kin are in contact with the ACT-team. The members of the network are trained to improve their communication and cope with stress. At this moment the RACT model is implemented in the Netherlands and will be evaluated on its effects (www.ract.nl).

*Parental role of fathers*

In this paragraph the emphasis is on fathers and their parental role. Although, in general, the share of the fathers in parenting has increased in recent decades, most mothers still deliver the largest part of parenting. In the period of the birth of their child sometimes fathers are neglected and afterwards remain in second place (Robertson, 2015). And, particularly in case of mental illness, other people may take over from the father whereas in case of mothers this is less likely to happen (Nicholson et al. 1999). In line with this, most literature on parenting with mental illness the mothers are the focus and there is ample knowledge on the characteristics and experiences of the fathers at hand (Nicholson et al., 2001).

In our interviews it became apparent that when a father experienced mental health problems and had to leave his job for a certain period, an opportunity was created to focus more on family life and parental tasks. This was beneficiary particularly in those cases when jobs have been stressful for a long time. The extra time and energy available for parenting was experienced as the positive side of becoming ill. Acknowledging this, investment in the parental role of a father in a crisis period can contribute to his recovery and improve the connection with his children.

## Children of parents with Mental Illness (COPMI)

Children of parents with mental illness are at a higher risk of developing a mental illness themselves. This is not only due to a generic higher vulnerability to mental illness but also to the possible risk of missing safety and a sense of security in their early years. Also, children interact directly with the mentally ill parent and, unintentionally, the child can be affected by the mood changes, anxieties, poor interactional skills and other forms of behavior that results from the illness. Many of these children have responsibilities in the household because of taking over the parental tasks (“parentification”). They are also exposed to other familial and contextual stressors that are associated with parental mental illness, such as, neglect, family stress, marital conflict, divorce, domestic violence, financial problems, and stigmatization and isolation. In the majority of cases, children are ‘silent’ about these burdens (Berne, 1970).

As described above, various preventive interventions have been worldwide developed that address the modifiable psychosocial risk mechanisms, enhance their resilience and reduce the risk that these children themselves develop mental health problems. However, healthy mechanisms like empowerment are also found developed by some of the children themselves. Thirty-four percent of the children of parents with mental illness report that they have not suffered from a difficult family life (Goossens & Speetjens, 2010). These children have become stronger in this situation. They obtain practical life experiences and cope with difficult situations and setbacks. In a positive way, they have empathy with emotions of other people. Unfortunately in the rest of this

group of children (66%) no such coping mechanisms seem to have developed, leaving them with a higher chance to suffer later on from mental problems.

From the perspective of their children, it is important that support and information around the problems adherent to the mental illness are shared in a safe and structured context. In many cases parents must be coached to do this in a way in which the needs of the children are recognized. Gladstone et al. (2011) emphasize that children's knowledge, understanding of mental illnesses and of the ways to access resources to acquire optimal information are mixed. Children's desire to be recognized as important to their parents' well-being conflicts with adults' perceptions that children should be protected from too much responsibility. These authors conclude that psychoeducation and peer-support group interventions for children are the best resources. Until now, in line with this reasoning parents and children are used to receive psychoeducation and treatment separately. It is a new development to combine education and treatment by nurses and social workers and to think in terms of families for these subjects (Falkov, 2012).

## Family and parental mental illness

The Family Model that is formulated by Falkov (2012) incorporates developmental, family, social and mental health domains. This model attempts to show the complete interaction between adult mental health issues, the child and parenting issues. The model also indicates that both risk factors and protective factors have their effect on what occurs within the family. Over time, the complexity and multi-directionality increases; just as the parent's mental health affects his or her parenting, the mental state and style of parenting affect the child's behavior and vice versa. Focusing on families requires cooperation among different organizations that are involved with one or more family members (Falkov, 2015).

The role of parents within their family on the light of recovery is discussed by Spaniol & Nelson (2015). Family members frequently express confusion and frustration when trying to navigate the complex and fragmented mental health care system. Family members tend to see themselves as seekers looking for mental health professionals who provide for their practical needs including information, education and support. Mental health professionals conversely see family members as needing therapy or mental health counseling. Professionals must be aware of the expectations of family members that differ from the expectations of these professionals. The professionals must also take into account the burden of the family members and, besides offering help to the 'identified patient', support other family members recognizing that families where a member has mental illness form a vulnerable group.

Relatives of people with a long-term disease reported that caring for their family member results in feelings of loss, negative effects on family life and restrictions in their own social and leisure activities (Magliano, Fiorillo, De Rosa, Malangone, Maj, 2005). In

the burden of care several aspects have to be taken into account such as the *personal consequences* for the family member for example the responsibility for the other family members and *aspects of the relationship* like being strained in interactions with the identified patient (Gerritsen and Van der Ende, 1994).

To have sufficient input of family members' own recovery processes, a *family mental health care plan* can be used. In this plan topics, that parents should work on as well as those that should be addressed by their children can be documented and assistance from professionals of several disciplines and services can also be incorporated. Rots-de Vries et al. (2011) wrote about developing a family plan as building bridges between the family and agencies that could offer help or assistance. During the meeting with the family members and the agencies involved, agreements were reached on what type of assistance would be delivered by which agency and on participation of the family members. To make this process comprehensible the principle of one family- one plan- one case manager is needed (Oude Vrielink, Koper, & Sterrenberg, 2013).

## Suggestions for further research

Several suggestions can be made to further study the subject of this thesis: in the field of epidemiology, where strategies for parents, children and relatives cope with mental illness in the family and to further evaluate the program of PARSS as a tool for professionals. This thesis showed that there is an explicit need for an international study on the year prevalence of parents with mental health problems, their children and the proportion of lost custody. The great variety found between the different countries requires a study using the same instruments at the same time in these countries. This study would best be executed in the US and the Netherlands, because especially between these countries big differences were found. But also, if possible, other countries can be included in such a study taking into account differences in the place family has in people's lives, attitudes around mental illness and the way the health system is organized.

It would also be very useful to expand the qualitative research by including children's views on the skills and strategies of their parents. As was the case in our study with parents, special attention should be given to those things that went well, the ways parents and children did adequately cope and the resources and context needed to achieve that. Possibly a combination of an interview with a parent, an interview with the parent's child and an interview with an involved professional in single or multiple studies will provide qualified evidence on ways to adequately deal with mental illness when parenting. Furthermore studies on the influence of the network of parents are advised as are studies on their capacities for support and/or for executing the parental role if the biological parent cannot fulfill this role. In cases of maternal mental health problems the parental role could be taken over by fathers, grandparents, closely related family members, the children and professionals.

The field would also gain by additional research on PARSS especially when a Randomized Controlled Trial could be developed. This study would best be done employing instruments used in the pilot study (chapter 5) presented in this thesis. It is advised that all types of parenting interventions be evaluated with the same instruments.

## General conclusion

Bearing and having a child can be confusing and a burden if one is a parent with mental health problems. On the other hand, parenting can also be a constructive part of a recovery process. Whereas in many cases, support by a close relative, peer support or professional support is needed, the attention for supporting these parents from a psychiatric rehabilitation point of view is still in its infancy. The same holds true for the perspective of recovery when working with parents with mental health problems. The development of family-oriented support by several services and working together with a family mental health care plan seems promising and an improvement compared to working on an individual basis with parents or with children.

However, also when working with families, a rehabilitative approach is needed, with promoting full community integration, improved quality of life, setting goals, using resources and the well-being of the families as the main guiding principles. Comprehensive and evidence based services for parenting offered by mental health institutions are yet in their early stages of development and more research is needed to gain knowledge on their feasibility and effectiveness. Although there is a variety of different programs and strategies described in the literature of which some are implemented in day to day practice, up till now no consequent, continued and evidence based support program for these parents can be found in mental health organizations in the Netherlands. For the benefit of this and later generations it is the responsibility of mental health care workers to provide adequate attention, a listening ear, personalized support and openness toward the rest of the network involved.

# SUMMARY

## Chapter 1: General Introduction

This thesis encompasses a series of studies on parenting by parents with mental health problems. The chapters describe, their personal recovery strategies, their development and an evaluation of a program for supported parenting. Considering all of the studies together, this thesis includes interviews with 100 parents and questionnaires and interviews with 154 professionals of (mental) health organizations.

In addition to the need for psychiatric and psychological treatment, many parents with mental health problems require support in their daily functioning to fulfill valued roles within their family and the community. Parents with mental health problems and their children are vulnerable to stigma and discrimination. Consequently, these parents do not feel free being open about their mental health problems and asking for support when needed to adequately provide for their children. In addition, especially in the area of parenting, these parents may feel that they are considered to be unfit with others doubting whether they can be responsible for making the right decisions. Additionally, when stigmatized parents do seek and obtain support, they often find that professionals exert too much control in raising their children and in performing other life tasks (Ackerson, 2003a). These parents may fear losing custody of their children.

Although the five studies of this thesis focus on the parental role from the parents' point of view, the children's point of view is also considered. Children of parents with mental illness (COPMI) experience several additional risks. For one, these children are at risk of developmental problems due to genetic heritability and the dysfunctional biological processes caused by maternal stress during pregnancy and psychosocial stress during a child's development. Effective interventions for children of parents with mental illness have been developed, as these children have a high risk of developing mental illness themselves. In the majority of cases, neither special programs nor other structural support for patients regarding their role as a parent are available, although in individual cases, support for the parental role might be given. The parental role is seldom a topic that is addressed in mental health care. There are few or no tools to support clients with mental health problems who wish to strengthen their parenting skills.

Professionals are not always familiar with supporting clients who have children and experience child-related needs. When professionals are aware of their client's parental role, they occasionally do not know how to manage the situation and show reticence to act. Instead of coaching the parents, professionals occasionally choose to work on solutions such as out-of-home placement of the children.

In our opinion, support for parents with mental health problems should always build upon their strengths and opportunities and should be based on goals formulated by the parents themselves. Supported parenting is best provided within the framework of the recovery process. Recovery is a journey of healing and transformation that enables a person with mental illness to live a meaningful life in the community (Deegan, 1988). Recovery involves working with experts by experience, peer groups and professionals

who have attitudes that are based on the principles of recovery. Leamy et al. (2011) identified five aspects of personal recovery: connectedness, hope and optimism, identity, meaning and purpose and empowerment (the so-called CHIME framework).

In the case of psychiatric problems, parents must be supported according to their own values and without judgment to facilitate their own development. Given the focus on parenting in this thesis, we wanted to investigate what parenting means to people with mental health problems. How can these parents be empowered to shape their role as a parent, to be an important source of affection and support and to set examples for their child?

In the past 15 years, the parental role has received increased attention in psychiatric rehabilitation (Nicholson et al. 2001; Mowbray et al. 2001, Nicholson & Deveney, 2009). Psychiatric rehabilitation promotes full community integration, improved quality of life and rehabilitation for persons who have been diagnosed with any mental health condition that seriously impairs their ability to lead a meaningful life (Farkas & Anthony, 1991). Psychiatric rehabilitation has a defined set of values, techniques, program practices and relevant outcomes that have been developed over the past thirty years. It emphasizes the fact that rehabilitation approaches should address the parental needs of the person in recovery.

The Parenting with Success and Satisfaction (PARSS) program was a newly developed intervention based on psychiatric rehabilitation that supports parents through professionals (Van der Ende, Venderink & Van Busschbach, 2010). The aim of PARSS was to support individuals in developing skills and accessing the resources necessary to be successful and satisfied in their parental role and in their family life (more details in chapter 5).

Being burdened with mental health problems affects one's material, psychosocial and physical needs. For example, negative consequences have been found regarding income, work, housing and possibilities for transport, childcare and housekeeping.

Although there is a growing awareness of the needs of these patients and of the parental responsibilities for the children involved, a clear picture of the type of support needed from professionals has been lacking.

We conducted a survey of patients' needs for support in their parenting role. Forty-seven parents (41 mothers and six fathers) participated, and 28 were single. Eighty percent (n=38) felt that their psychiatric problems interfered with the relationships they had with their children. Although almost all (n=44) said that they had received enough professional care, half of them wanted types of support that regular mental health care did not supply: practice in starting conversations with a child, ways to deal with specific aspects of child behavior, nurturance support, legal assistance with custody, child support, and help in arranging support from peers. Those with no direct responsibilities in raising their children (n=9) wanted more and better contact with their children. For all participants, an important issue was finding a good balance between being a parent and creating a life for themselves within the constraints of psychiatric illness.

## Chapter 2. Parents with severe mental illness: Epidemiological data

National population data and surveys on mental illness were used to estimate the number of parents with mental illness. Of all patients with Severe Mental Illness (SMI), 48% were estimated to have children. The total number in the year 2009 was 68,000 parents; this represented 0.9% of the Dutch population between 18 and 65 years.

Considering the fact that one out of two patients with SMI was estimated to have a child, professional care providers need to be aware of the possible need for support in parenting. The lack of these data in registrations has been communicated, among other topics, in questions posed to the Dutch government. Better problem registration in the parent-child relationship is necessary to adequately manage the provision of care on both the individual level and the macro level.

The numbers indicate that we are dealing with an extensive target group that is possibly seeking support with parenting. Furthermore, it is important to emphasize that an adequate supply of (mental health) care would prove helpful not only to the patient but also to the children involved. With extra support, situations of disruption can be prevented and parents can continue to exercise their parenting in one form or another. Intensive collaboration with child and youth care institutions could help accomplish this goal.

## Chapter 3. Strategies for parenting by mothers and fathers with a mental illness

Currently, we know that a large proportion of people in mental health care struggle with the combination of coping with their mental health problems and caring for their children. However, how these mothers and fathers address challenges in their parental role is less clear, nor do we know what role parenting plays in their recovery processes. To learn more about these strategies and processes, a qualitative, exploratory approach was implemented. For this study, we used the research question: “What are the strategies that parents with a mental illness use in order to be successful in their parental role?”

The experiences of 19 mothers and eight fathers with a mental illness were explored using in-depth interviews. In this study, all 27 participants’ youngest children were younger than 19 years old. A narrative approach (Miles & Huberman, 1994) was used with extra attention paid to the patterns of inter-connection in the data that differed from what might have been expected. These were the so-called ‘follow-up surprises’ that had the potential to reveal patterns that could be very informative. An in-depth interview guide was used to elicit data about parents’ experiences. The guide comprised open-ended questions such as: ‘What does parenting mean to you?’ ‘What are the effects of your mental illness on parenting?’ and ‘What strategies do you use to overcome your disabilities?’ From their responses, themes emerged and codes were assigned. Recurrent issues were identified by a thematic analysis of the data using Atlas-TI (a software program for the analysis of qualitative data, Muhr, 2004).

In general, participants reported that their mental illness had a negative effect on their parental role, with increased feelings of inadequacy and the additional fear of transferring their problems to their children. Although all interviewed parents mentioned diverse negative effects of their mental health problems on parenting, they also found strength by meeting this role's challenges. Parents with a mental illness often felt a heightened sense of responsibility, and this helped them stay alert when interacting with their children. Due to their mental health problems, parents' rhythm of life was disrupted, but because of the responsibility of caring for their children, a new rhythm and structure was developed.

Developing activities that interested both the child and the parent provided avenues for emerging strength. Despite feelings of inadequacy, interviewees also described how children enriched and structured their lives and were not only a responsibility but also served as a distraction from their problems. A married mother with two children aged 6 and 10 years old explained:

> *Our children helped us because they forced us to structure our lives: waking in the morning, making breakfast, taking children to school, getting them from school, lunch …*

The women and men in our study reported that fulfilling the parental role provided a valued identity. Creating a daily routine, pursuing shared interests and activities, solving problems and finding strength in meeting parenting challenges contributed to their personal growth and recovery. Their relationships with children, family, school contacts and community members allowed parents to express their feelings and to seek support through informal and professional networks.

The main strategies that we found regarding the parental role of people with mental illness were being fully dedicated to the parental role, finding a good balance between the attention given to one's own life and to parenting, and finding adequate sources of support.

Peer groups can provide valuable help, and mental health workers can support parents in setting self-selected parenting related goals. Nurses can support and coach patients who are identified as parents and whose self-chosen parenting related goals are set to be addressed. A family focused approach can be used professional workers to prevent problems with parents' children and families, identify their strengths as well as vulnerabilities, address their challenges and to build resilience.

Regarding the role of the father, we found a number of fathers who truly took responsibility for their children and were managing their own mental health problems in a very constructive way. To this end, they sometimes needed to develop new competencies or discover unknown possibilities. Although most fathers felt limited in their role, the examples showed that fathers with mental health problems could find ways to play a larger role. In our interviews, it became apparent that if a father experienced mental health problems and had to leave his job for a certain period of time, he might receive the opportunity to focus more on his family. Accordingly, investment in the father role during

a crisis could contribute to his recovery or to supporting his spouse and improving the connection with his children. As direct contact is a prerequisite for developing adequate functioning in the parental role and for positive relationships with children, spouses and partners should be encouraged to allow fathers opportunities to provide caring.

## Chapter 4. Professionals' opinions on support for people with chronic illness in their roles as parents in mental and general health care

Specific services for parents are scarce, as are programs to train social workers and nurses on how to support people with chronic illness in their roles as parents. The study presented in this chapter addressed the question of whether hospital staff members provided supported parenting to their patients and especially whether the support varied between mental health facilities and general hospitals.

This study was performed with a focus on the possible differences between staff members in organizations who were trained in supported parenting and those who were not. The comparison provided a snapshot of the availability of supported parenting and identified organizations that could serve as an example for other organizations.

In an explorative study, we investigated the similarities and differences between mental health organizations and general hospitals in providing support to parents. Using a cross-sectional design, information on supported parenting was collected through an internet questionnaire directed at professionals (N=128). The first group of respondents in this study (n=41) comprised workers in two provincial Dutch mental health organizations in which professionals had previously received a four-day training in the parenting support program PARSS. The second group of respondents (n=36) consisted of professionals from two nearby mental health organizations where no such training had been offered. In each of the four mental health organizations in these two groups, workers from a variety of departments (long stay/short stay, inpatient/outpatient care) were invited to participate. The third group of respondents (n=51) included health workers from three Dutch general hospitals in long-stay departments with specialties such as oncology, pulmonary illness and burns. After receiving an invitation by email, the participants completed web-based questionnaires.

Twice as many workers in the general hospitals found opportunities to support parents than in mental health organizations that were not trained in supported parenting. In the general hospitals, 73% found that their organization paid sufficient attention to parenting. In the mental health organizations where training in supported parenting was provided, 61% of the professionals stated that their organization adequately facilitated parental support. However, in the mental health organizations without such training, significantly fewer professionals, 25%, felt that their organization provided enough support to the parental role of patients.

## Chapter 5. Parenting and psychiatric rehabilitation: Can parents with severe mental illness benefit from a new approach?

The newly developed program Parenting with Success and Satisfaction (PARSS) was considered an addition to other types of treatment and could be implemented in either inpatient or outpatient settings (Van der Ende et al., 2010). The PARSS intervention included three workbooks for parents to help them achieve their parenting goals using a guided self-help approach. For parents, PARSS provided a way of working on their self-selected goals regarding their own well-being in combination with a focus on their child's strengths and needs. Some components of the intervention could be used by parents themselves as a self-help strategy. Other components of the intervention were best completed with the assistance of a mental health practitioner (i.e., a social worker, nurse, psychologist and, in some cases, a psychiatrist). Three manuals were available: *Workbook I. Assessing functioning in the parental role* outlined explicit skills and recommended resources for all parents regarding fulfilling the parental role, *Workbook IIa. Strengthening the parental role* encouraged parents living with their children to describe what the parental role meant to them, and *Workbook IIb. Taking back or expanding the parental role* was designed for parents not living with their children.

If the contact between practitioners and parents had a single emphasis on parenting goals, the entire intervention took about a year on average, with weekly sessions. The training of mental health practitioners to implement PARSS took a total of 4 days, with longer intervals between sessions in the last phase of training to facilitate clinical supervision. PARSS may also be useful to parents during or after a psychiatric hospitalization.

The aim of conducting the pilot study was to explore the initial experiences with and impact of PARSS. Data were collected in structured interviews with parents, their close relatives and their mental health practitioners at enrollment (T0) and 1 year later (T1). Changes in the PARSS intervention group (N=11) were compared with changes in a control group (N=15). The outcome measures included parenting satisfaction, parenting success, empowerment, and reported quality of life. Additional process data were obtained on the parents' relationship with the practitioner, the quality of contacts, satisfaction with the intervention and program fidelity.

Quality of life improved significantly in the intervention group compared with the control group. There was a trend of parenting satisfaction increasing after 1 year in the PARSS group, with no such trend in the control group. Parents' reports of empowerment did not change for either group. The process measures showed that both parents and practitioners expressed satisfaction with the intervention.

This intervention, implemented by mental health practitioners, has the potential to function as a useful tool for supporting parents. Attention must be paid to enhancing the intervention implementation and fidelity.

## Chapter 6: General Discussion

Our qualitative exploratory study emphasized the need for professionals to address parent-child interactions. We conceptualized a model comprising the needs, barriers, motivation, strategies and goals with regard to the parental role of persons with mental health problems. The model started with the parental needs of people with mental health problems. Next were the barriers that might obstruct the achievement of good parental goals, such as discrimination, fear of losing custody of one's children and worries about transferring mental health problems to children. Being motivated by stimuli from their families and/or by strategies developed along the way enabled parents to overcome these barriers. Final outcomes such as a satisfying parental role could then be reached.

Our diverse series of studies showed that raising children while also managing mental health problems was challenging but could also form an important step in a parent's recovery process. For a majority of the parents, support from a close relative, peer support or professional support was needed. When stigma and fear of discrimination or worse, loss of custody of the child, negatively affected the chances that a parent would speak openly about this need, a rehabilitative approach, beginning with the strategies already used by the parents, could possibly overcome this barrier.

In this way, thinking in terms of families, mental health organizations can accomplish much more regarding parents with mental health issues and their children. Some professionals have shown a reticence to act in situations of parental violence and neglect. They have found it difficult to coach and show solidarity with parents while also staying alert for the safety of the parents' children. Training in how to address these situations is needed to overcome the risk, on the one hand, that professionals will neglect a situation that is dangerous to the child or, on the other hand, that overly rigorous solutions will be taken such as bringing children to another location by force and removing parental custody.

Working on parenting can be comprehensive and integrative. If people with mental illness stay within the communities and if family members are not disassembled, there are more opportunities to work with the network as a whole and the resources within, such as in the so-called family model (Falkov, 2012).

To ensure sufficient input of family members' own recovery processes, a family mental health care plan can be used. In this plan, topics that parents should work on as well as those that should be addressed by their children can be documented, and assistance from professionals can also be incorporated. The starting points of these plans should be first addressing people's own strengths, next activating social networks and volunteers and finally including support from professionals.

Children can be unintentionally affected by the mood changes, anxieties, poor interactional skills and other forms of behavior that result from the mental health problems of their parents. Children are also exposed to other familial and contextual stressors that are associated with parental mental illness, such as neglect, family

stress, marital conflict, divorce, domestic violence, financial problems, stigmatization and isolation. To reduce these risks in children and to enhance their resilience, various preventive interventions have been developed worldwide that address modifiable psychosocial risk mechanisms. There is an urgent need for these programs to be implemented in such a way that they become available to every child who can benefit from them. The same holds true for their parents.

In this thesis, recommendations were given as to the content and organization of support and the research that should accompany its further development and implementation. As for now, professionals and parents should work together constructively in openness, using each other's strengths and listening to how people have coped, both successfully and unsuccessfully. Since there is more to be learned along the way than we can take with us when we start a journey.

# SAMENVATTING

## KWETSBAAR OUDERSCHAP

## EEN STUDIE NAAR OUDERS MET PSYCHISCHE AANDOENINGEN: STRATEGIEËN EN STEUN

## Hoofdstuk 1

*Algemene introductie*

Dit proefschrift omvat een aantal onderzoeken over ouderschap van ouders met psychische aandoeningen. De hoofdstukken van dit proefschrift beschrijven de persoonlijke herstelstrategieën, de ontwikkeling van deze ouders en een evaluatie van een programma voor begeleid ouderschap. Alle onderzoeken voor dit proefschrift samen bevatten interviews met 100 ouders en ook de resultaten van schriftelijke vragenlijsten en mondelinge interviews met 154 professionele hulpverleners.

Naast de behoefte aan psychiatrische en psychologische behandeling, hebben veel ouders steun nodig om een gewaardeerde rol in hun gezin en in de samenleving te vervullen. Ouders met psychische aandoeningen en hun kinderen zijn kwetsbaar voor stigma's en discriminatie. Een gevolg hiervan is dat deze ouders zich niet vrij voelen om open te zijn over hun psychische aandoeningen en om steun te vragen als dat nodig is voor het vervullen van een gepaste rol voor hun kinderen.

Bovendien kunnen deze ouders, speciaal op het gebied van ouderschap, zelf het gevoel krijgen dat ze beschouwd worden als ongeschikte ouders, terwijl anderen betwijfelen of ze verantwoordelijk kunnen zijn voor het maken van de juiste keuzes. Als gestigmatiseerde ouders wel steun krijgen, vinden ze vaak dat hulpverleners te veel controle uitoefenen op het opvoeden van hun kinderen en op het uitvoeren van andere belangrijke taken in het leven (Ackerson, 2003a). Deze ouders kunnen bang worden voor het verlies van hun wettelijk ouderlijk gezag.

Hoewel de verschillende onderzoeken in het kader van dit proefschrift zich richten op de ouderrol vanuit het gezichtspunt van de ouders, is ook het gezichtspunt vanuit de kinderen beschreven. Kinderen van Ouders met Psychische Problemen (KOPP) ervaren een aantal extra risico's. Deze kinderen hebben kans op ontwikkelingsproblemen door erfelijkheid, door schadelijke biologische processen vanwege de stress van de moeders tijdens de zwangerschap en door psychosociale stress tijdens de eigen ontwikkeling. Er zijn effectieve interventies ontwikkeld voor kinderen van ouders met psychische aandoeningen, aangezien deze kinderen het risico lopen om zelf een psychische aandoening te ontwikkelen.

Veelal is er geen speciaal programma of structurele steun beschikbaar voor patiënten in hun rol als ouder. De ouderrol is zelden een onderwerp dat wordt besproken in de geestelijke gezondheidszorg. Maar in individuele gevallen geven hulpverleners wel steun aan de ouderrol. Er zijn beperkte programma's beschikbaar om ouders met psychische aandoeningen die hun ouderschapsvaardigheden willen versterken, te ondersteunen.

Hulpverleners zijn niet altijd vertrouwd met de steun voor patiënten met kinderen. Als hulpverleners zich bewust zijn van de ouderrol van een patiënt, weten zij in bepaalde situaties vaak niet hoe ze moeten reageren en hebben zij last van handelingsverlegenheid. In plaats van het coachen van ouders, kiezen hulpverleners soms voor rigoureuze ingrepen zoals uithuisplaatsing van kinderen.

Naar onze mening behoort de steun voor ouders met psychische aandoeningen altijd te worden gebouwd op hun kracht en mogelijkheden, en te worden gebaseerd op doelen die door ouders zelf zijn geformuleerd. Begeleid ouderschap kan het beste worden uitgevoerd in het raamwerk van de herstelbenadering en de psychiatrische rehabilitatiebenadering.

Herstel is een reis van genezing en transitie die iemand met psychische aandoeningen in staat stelt om een betekenisvol leven in de samenleving te hebben (Deegan, 1988). Herstel houdt in: het werken met ervaringsdeskundigen, bondgenoten en hulpverleners die attituden gebaseerd op herstel, hebben. Met betrekking tot attituden stelden Leamy et al. (2011) vijf aspecten van persoonlijk herstel vast: verbondenheid, hoop/optimisme, identiteit, betekenis/doel en empowerment.

Als er sprake is van psychische aandoeningen, moeten ouders worden ondersteund volgens hun eigen waarden en zonder oordeel, om hun eigen ontwikkeling effectief te kunnen bevorderen. Met het accent op ouderschap wilden we in dit proefschrift onderzoeken wat dit betekent voor ouders met psychische aandoeningen. Hoe kunnen deze ouders versterkt worden in hun ouderrol, een belangrijke bron van affectie en steun zijn en voorbeelden stellen voor hun kinderen? In de afgelopen vijftien jaar heeft de ouderrol toenemende aandacht gekregen in de psychiatrische rehabilitatie (Nicholson et al., 2001; Mowbray et al. 2001, Nicholson & Deveney, 2009).

Belast zijn met psychische aandoeningen heeft invloed op materiële, psychosociale en fysieke behoeften. Er zijn bijvoorbeeld negatieve gevolgen gevonden met betrekking tot inkomen, werk, huisvesting en mogelijkheden voor transport, kinderopvang en huishouden.

Hoewel er een toenemend bewustzijn is van de behoeften van deze ouders en van de ouderlijke verantwoordelijkheden voor de kinderen, ontbreekt er nog een helder beeld van het type steun dat professionals zouden kunnen bieden. We hebben een onderzoek naar de ondersteuningsbehoeften van patiënten in hun ouderrol uitgevoerd. Er namen 47 ouders (41 moeders en 6 vaders) aan deel; 28 van hen waren alleenstaand. Zij zijn geïnterviewd aan de hand van een vragenlijst met gestructureerde én open vragen. Van hen voelde 80% dat hun psychiatrische problemen schade toebrachten aan hun relatie met hun kinderen. Bijna allen (n=44) zeiden dat ze genoeg professionele steun ontvingen, terwijl de helft ook vormen van steun wilde die de reguliere geestelijke gezondheidszorg niet bood: oefening met het starten van een gesprek met een kind, manieren om met specifieke aspecten van het gedrag van kinderen om te gaan, steun voor kinderen en hulp bij het organiseren van steun van bondgenoten. Degenen die geen directe verantwoordelijkheden hadden in de opvoeding van de kinderen, wilden meer en beter contact met de kinderen. Voor alle deelnemers was het een belangrijk punt om een goede balans te vinden tussen ouderschap en het hebben van een eigen leven binnen de beperkingen van een psychische aandoening.

Psychiatrische rehabilitatie bevordert volledige integratie in de samenleving, en verbetert kwaliteit van leven en rehabilitatie van mensen bij wie een psychische aandoening is gediagnosticeerd die de mogelijkheid om een betekenisvol leven te leiden blokkeert (Farkas & Anthony, 1991). Deze rehabilitatie omvat een vastgestelde reeks van waarden, technieken, methoden en relevante uitkomsten, die gedurende de laatste dertig jaar zijn ontwikkeld. Ook benadrukt dit type rehabilitatie het feit dat rehabilitatiebenaderingen de ouderlijke behoeften van de herstellende mensen moeten aanspreken. De methodiek "Ouderschap met Succes en Tevredenheid" (OST) is een nieuw ontwikkelde interventie, gebaseerd op psychiatrische rehabilitatie waarmee hulpverleners ouders ondersteunen (Venderink & Van der Ende, 2006). Het doel van OST is om individuen te ondersteunen bij het ontwikkelen van vaardigheden en toegang te krijgen tot de hulpbronnen die nodig zijn om succesvol en tevreden te zijn in ouderrol en gezinsleven.

## Hoofdstuk 2

*Ouders met ernstige psychische aandoeningen: epidemiologische gegevens*

Landelijk bevolkingsonderzoek en specifiek onderzoek naar psychische aandoeningen zijn gebruikt om het aantal ouders met ernstige psychische aandoeningen (EPA) te schatten. Van alle patiënten met ernstige psychische aandoeningen is de schatting dat 48% kinderen heeft. Het totale aantal in het jaar 2009 was 68.000 ouders; dit betekende 0,9% van de Nederlandse populatie tussen 18 en 65 jaar oud.

In aanmerking genomen dat naar schatting één van de twee patiënten met EPA een kind heeft, wordt er van professionele hulpverleners verwacht dat zij zich bewust zijn van de mogelijke behoefte aan steun bij ouderschap. Het gebrek aan registratie van het hebben van kinderen is besproken in de Tweede Kamer (2009). Een betere registratie van problemen tussen ouders en kinderen is nodig om adequaat zorg te kunnen bieden op individueel en op macroniveau.

De genoemde aantallen illustreren dat we te maken hebben met een grote doelgroep, die mogelijk steun zoekt voor ouderschap. Daarnaast is het belangrijk om te benadrukken dat een passend aanbod van (geestelijke gezondheids)zorg bewijst tot steunte dienen, niet alleen voor de ouder maar ook voor de betreffende kinderen. Met extra steun kunnen dreigende situaties van ontwrichting worden voorkomen en ouders hun ouderschap in de een of andere vorm blijven uitoefenen. Een intensieve samenwerking met jeugdzorginstellingen biedt daarvoor een mogelijkheid.

## Hoofdstuk 3

*Strategieën voor ouderschap van moeders en vaders met psychische aandoeningen*

Inmiddels weten we dat een groot deel van de mensen die geestelijke gezondheidszorg ontvangen, kampt met de combinatie van omgaan met hun psychische aandoeningen en de zorg voor hun kinderen. Echter, hoe deze moeders en vaders zich richten op de uitdagingen in hun ouderrol, is minder duidelijk. Ook weten we niet welke rol ouderschap

speelt in herstelprocessen. Om meer te weten te komen over deze strategieën en processen is een kwalitatief, exploratief onderzoek uitgevoerd. Voor dit onderzoek namen we de volgende vraag als uitgangspunt: “Wat zijn de strategieën die ouders met psychische aandoeningen gebruiken om succesvol te zijn in de ouderrol?”

De ervaring van 19 moeders en 8 vaders met psychische aandoeningen hebben we verkend via diepte-interviews. In dit onderzoek waren de jongste kinderen van alle 27 deelnemers jonger dan 19 jaar. Er is een narratieve benadering (Miles & Huberman, 1994) gebruikt, met extra aandacht voor de patronen van onderlinge verbondenheid in de gegevens die afweken van wat verwacht kon worden. Dit waren de zogeheten ‘opeenvolgende verrassingen’, die de mogelijkheid hadden om patronen te onthullen die informatief waren. Er is gebruik gemaakt van een interviewschema om informatie over de ervaringen van de ouders in kaart te brengen. Het schema bevatte open vragen zoals: “Wat betekent ouderschap voor u?”, “Wat zijn de effecten van uw psychische aandoeningen op uw ouderschap?” en “Welke strategieën gebruikt u om uw problemen te overwinnen?” Vanuit de antwoorden, werden thema’s gedestilleerd, waaraan codes werden toegekend. Terugkerende kwesties zijn geïdentificeerd door een thematische analyse van de gegevens met gebruikmaking van Atlas-TI (een softwareprogramma voor de analyse van kwalitatieve gegevens; Muhr, 2004).

Over het algemeen rapporteerden de deelnemers dat de psychische aandoeningen een negatief effect hadden op hun ouderrol, met een toenemend gevoel van ontoereikendheid en daarbij de angst van het overbrengen van hun problemen op hun kinderen. Hoewel alle geïnterviewde ouders diverse negatieve effecten van hun psychische aandoeningen op ouderschap noemden, vonden ze ook kracht om aan de uitdagingen van deze rol te voldoen.

Deze ouders ervoeren vaak een toegenomen gevoel van verantwoordelijkheid en dit hielp hen om alert te blijven in de interactie met hun kinderen. Als gevolg van de psychische problemen was het levensritme verstoord, maar vanwege de verantwoordelijkheid om voor hun kinderen te zorgen werden een nieuw ritme en structuur ontwikkeld.

Het ontwikkelen van activiteiten die zowel het kind als de ouders interesseren, gaf richting aan de toenemende kracht. Ondanks gevoelens van ontoereikendheid, beschreven geïnterviewden hoe kinderen hun leven verrijkten en structureerden, de ouders waren niet alleen verantwoordelijk maar de kinderen functioneerden ook als een afleiding voor hun problemen. Een getrouwde moeder met twee kinderen van zes en tien jaar verklaarde:

> *Onze kinderen hielpen ons omdat ze ons dwongen om ons leven te structureren: ’s morgens opstaan, ontbijt maken, kinderen naar school brengen. Daarna van school halen, lunch, ……..*

De vrouwen en de mannen in ons onderzoek vertelden dat het vervullen van een ouderrol hen een gewaardeerde identiteit gaf. Het creëren van een dagelijkse routine, zoeken van gedeelde interesses en activiteiten, oplossen van problemen en het vinden van kracht bij

het zoeken van uitdagingen voor het ouderschap, droegen bij tot hun persoonlijke groei en herstel. Hun relaties met de kinderen, familie, school en buren gaven aan ouders de mogelijkheid om hun gevoel te uiten en om steun te zoeken via informele en professionele netwerken.

De belangrijkste strategieën met betrekking tot de ouderrol van mensen met psychische aandoeningen waren: volledig toegewijd zijn aan de ouderrol, een goede balans vinden tussen de aandacht voor iemands eigen leven en het ouderschap, en het vinden van goede hulpbronnen.

Groepen van bondgenoten kunnen waardevolle hulp bieden, en hulpverleners kunnen ouders ondersteunen bij het opstellen van door hen zelf uitgekozen doelen die met ouderschap te maken hebben. Hulpverleners kunnen een gezinsgeoriënteerde aanpak gebruiken om problemen van de kinderen van patiënten en van de familie te voorkomen, om hun kracht en hun zwakheden te ontdekken, om zich te richten op hun uitdagingen en om hun veerkracht te stimuleren.

Met betrekking tot de vaderrol vonden we diverse vaders die echt de verantwoordelijkheid voor hun kinderen namen en die op een constructieve manier aan hun eigen psychische problemen werkten. Hiervoor moesten zij soms nieuwe competenties ontwikkelen en onbekende mogelijkheden verkennen. Hoewel de meeste vaders zich beperkt voelden in hun rol, toonden concrete voorbeelden aan dat vaders met psychische aandoeningen manieren konden vinden om een grotere rol te spelen. In onze interviews werd duidelijk dat als een vader psychische problemen ervoer en als hij uit het werk raakte voor een bepaalde periode, hij de gelegenheid kreeg om zich meer op zijn gezin te concentreren. Investering in de vaderrol gedurende een crisis droeg bij aan herstel of steun aan de partner en verbetering van de band met de kinderen. Aangezien direct contact een voorwaarde is voor adequaat functioneren in de vaderrol en voor positieve relaties met kinderen, behoren partners te worden aangemoedigd om vaders toe te staan om voor de kinderen te zorgen.

## Hoofstuk 4

*Meningen van hulpverleners over de steun aan mensen met chronische ziekten in hun rol als ouders in geestelijke en algemene gezondheidszorg*

Specifieke voorzieningen voor ouders zijn schaars, evenals programma's om maatschappelijk werkers en verpleegkundigen te trainen in de steun aan mensen met chronische ziekten in hun ouderrol. Het onderzoek dat in dit hoofdstuk wordt gepresenteerd, richt zich op de vraag of de hulpverleners begeleid ouderschap aan hun patiënten aanboden en of de steun van instellingen voor geestelijke gezondheidszorg verschilde van de steun van de algemene ziekenhuizen.

Het onderzoek is uitgevoerd met het accent op mogelijke verschillen tussen hulpverleners in organisaties die werden getraind in begeleid ouderschap (OST) en hulpverleners die deze training niet hebben gehad. De vergelijking gaf een inkijk in de

beschikbaarheid van begeleid ouderschap en signaleerde organisaties die als voorbeeld voor andere organisaties konden dienen.

Met een exploratief onderzoek bestudeerden we de overeenkomsten en verschillen tussen instellingen voor geestelijke gezonheidszorg en algemene ziekenhuizen met betrekking tot zorg voor ouders. Met gebruikmaking van een cross-sectioneel design verzamelden we informatie via een internetvragenlijst gericht op hulpverleners (N=128). De eerste groep respondenten van dit onderzoek (n=41) bevatte werkers van twee provinciale organisaties voor geestelijke gezondheidszorg, waarvan hulpverleners voorheen een vierdaagse training in het OST-programma hadden gevolgd. De tweede groep respondenten (n=36) bestond uit hulpverleners van twee nabijgelegen organisaties voor geestelijke gezondheidszorg waar een dergelijke training niet was gegeven. In alle vier organisaties voor geestelijke gezondheidszorg waren werkers van verschillende afdelingen (langdurend/kortdurend verblijf, intra-/extramuraal) uitgenodigd om deel te nemen. De derde groep deelnemers (n=51) bestond uit medewerkers van drie algemene ziekenhuizen met specialiteiten als oncologie, longziekten en brandwonden. Nadat de deelnemers per e-mail een uitnodiging hadden ontvangen, vulden zij via internet een vragenlijst in.

Tweemaal zoveel werkers in de algemene ziekenhuizen vonden gelegenheid om ouders te ondersteunen dan de werkers in de instellingen voor geestelijke gezondheidszorg die niet waren getraind in begeleid ouderschap.

In de algemene ziekenhuizen vond 73% van de deelnemers dat hun organisatie voldoende aandacht besteedde aan ouderschap. In de organisaties voor geestelijke gezondheidszorg waar training in begeleid ouderschap was gegeven, stelde 61% van de hulpverleners dat hun organisatie op een adequate manier begeleid ouderschap faciliteerde. Echter, in de organisaties voor geestelijke gezondheidszorg organisaties zonder een dergelijke training, gaven significant minder hulpverleners, namelijk 25%, aan dat hun organisatie genoeg steun aan de ouderrol van patiënten bood.

## Hoofdstuk 5

*Ouderschap en psychiatrische rehabilitatie: kunnen ouders met ernstige psychische aandoeningen profiteren van een nieuwe benadering?*

De nieuw ontwikkelde methodiek “Ouderschap met Succes en Tevredenheid” (OST, Venderink & Van der Ende, 2006) is een aanvulling op andere vormen van behandeling en kan worden geïmplementeerd in intramurale en extramurale settingen. De OST-methodiek bevat drie werkboeken voor ouders om doelen voor ouderschap te bereiken, waarbij gebruik gemaakt wordt van een begeleide zelfhulpbenadering. Voor ouders voorziet OST in een manier van werken aan door henzelf gekozen doelen met betrekking tot hun eigen welzijn in combinatie met een nadruk op de kracht en de behoeften van hun kind. Sommige onderdelen van de interventie kunnen worden gebruikt door ouders zelf als een zelfhulpstrategie. Andere componenten van de interventie kunnen het best

worden ingevuld met assistentie van een hulpverlener (bijvoorbeeld een maatschappelijk werker, verpleegkundige, psycholoog en in enkele gevallen een psychiater). Er zijn drie werkboeken beschikbaar: I. *Huidig functioneren in de ouderrol*; IIa. *Versterken van de ouderrol als het gezin onder één dak woont*; IIb.
*Hernemen of uitbreiden van de ouderrol, vader of moeder woont apart van het kind*.

Als het contact tussen hulpverlener en ouders alleen gericht was op ouderschapsdoelen, nam de gehele interventie gemiddeld ongeveer een jaar in beslag, met wekelijkse sessies. De training van hulpverleners om OST te implementeren duurde totaal vier dagen met langere intervallen tussen sessies in de laatste trainingsfase om supervisie over klinische begeleiding te faciliteren.

OST kan ook bruikbaar zijn voor ouders gedurende en na een psychiatrische hospitalisatie. Het doel van een pilotonderzoek was om de eerste ervaringen met en effecten van OST te verkennen.

We verzamelden gegevens via gestructureerde interviews met ouders, hun familie en hun hulpverleners bij de start (T0) en één jaar later (T1). Veranderingen in de interventiegroep (de OST-groep; n=11) vergeleken we met veranderingen in de controlegroep (n=15). De uitkomstmaten waren tevredenheid met ouderschap, succes in ouderschap, empowerment en ervaren kwaliteit van leven. Verdere procesgegevens werden verkregen over de ervaren relatie tussen ouder en hulpverlener, over de kwaliteit van de contacten, over de tevredenheid met de interventie en over de betrouwbaarheid van de toepassing van de methodiek.

De kwaliteit van leven verbeterde significant in de interventiegroep, vergeleken met de controlegroep. Er was een trend dat de tevredenheid met het ouderschap toenam na een jaar; deze trend was in de controlegroep niet waar te nemen. De rapportage van de ouders over empowerment liet in beide groepen geen verandering zien. De antwoorden op de vragen over het proces toonden tevredenheid aan bij zowel ouders als hulpverleners.

Het implementeren van deze interventie bij hulpverleners heeft de potentie om als een bruikbaar gereedschap voor de ondersteuning van ouders te functioneren. Er dient aandacht te worden besteed aan de versterking van de implementatie van de interventie en aan de betrouwbaarheid van de toepassing (*fidelity*). Een groepsgewijze aanpak van deze methodiek kan ook een goed perspectief bieden.

## Hoofdstuk 6

*Algemene discussie*

Ons kwalitatief, exploratief onderzoek benadrukte de noodzaak voor hulpverleners om zich op ouder-kindinteracties te richten. Daarna beschreven we een model met daarin de behoeften, belemmeringen, motivatie, strategieën en doelen voor de ouderrol van mensen met psychische aandoeningen. Het model begon bij de beschrijving van de ouderschapsbehoeften, vervolgens waren er de belemmeringen die het behalen van

goede ouderschapsdoelen tegenhouden (zoals discriminatie, angst voor het verlies van het wettelijk ouderlijk gezag en zorgen om het overbrengen van de eigen psychische problemen op de kinderen). Gemotiveerd door prikkels uit het gezin en/of strategieën die door de tijd werden ontwikkeld, werden ouders in staat gesteld om over deze belemmeringen heen te stappen. Zij wisten vervolgens positieve eindresultaten te bereiken, zoals een bevredigende ouderrol.

Onze onderzoeken lieten zien dat kinderen opvoeden tegelijkertijd met het hanteren van psychische problemen een uitdaging vormt, maar ook een belangrijke stap in het herstelproces van de ouder kan zijn. Voor de meerderheid van de ouders was steun van een familielid, vriend, bondgenoot of professionele hulpverlener nodig. Als de angst voor het stigma, voor discriminatie of erger nog, de angst voor het verlies van het ouderlijk gezag, de kans dat ouders open praten negatief beïnvloedt, kan een rehabilitatiebenadering, beginnend met strategieën die al door de ouders worden gebruikt, deze belemmeringen wellicht overwinnen.

Via het denken in termen van gezinsbenadering kunnen organisaties voor geestelijke gezondheidszorg veel meer bereiken voor gezinnen waarin een ouder een psychische aandoening heeft. Sommige hulpverleners hebben een handelingsverlegenheid in situaties waar sprake is van geweld of verwaarlozing. Ze vinden het moeilijk om te coachen en solidariteit met ouders te tonen plus tegelijkertijd alert te zijn op de veiligheid van de kinderen. Training in hoe men moet handelen in deze situaties is nodig om hiermee aan de ene kant het risico te voorkomen dat hulpverleners bepaalde feiten ontkennen, wat gevaarlijk is voor een kind, en om aan de andere kant vermijden dat te rigoureuze beslissingen worden genomen (zoals het kind met dwang naar een andere locatie brengen en het aan het ouderlijk gezag onttrekken).

Het werken aan ouderschap kan samenhangend en integratief plaatsvinden. Als mensen met psychische aandoeningen in de samenleving blijven en als een gezin niet uit elkaar gehaald wordt, zijn er meer mogelijkheden om met het netwerk als geheel en de hulpbronnen daarbinnen te werken, zie ook het zogeheten gezinsmodel (Falkov, 2012).

Om voldoende input van de eigen herstelprocessen van gezinsleden te garanderen kan een gezinszorgplan worden gebruikt. In dit plan kunnen onderwerpen waaraan ouders en kinderen gaan werken en de steun van hulpverleners worden beschreven. De start van deze plannen behoort te liggen bij de eigen kracht van de betreffende ouders en kinderen, vervolgens gericht te zijn op het activeren van vrijwilligers en sociale netwerken en ten slotte, indien nodig, zou er professionele steun bij betrokken moeten worden.

Kinderen kunnen onbedoeld aangetast worden door de stemmingswisselingen, angsten, beperkte communicatievaardigheden en andere gedragingen die ontstaan vanuit de psychische aandoeningen van hun ouders. Kinderen worden ook blootgesteld aan andere gezins- en omgevingsstressoren (die worden geassocieerd met ouderlijke psychische aandoeningen), zoals verwaarlozing, gezinsstress, huwelijksconflicten, scheiding, huiselijk geweld, financiële problemen, stigmatisering en isolement. Om deze

risico's voor kinderen te verkleinen en om hun veerkracht te vergroten, zijn wereldwijd verschillende preventieve interventies ontwikkeld die zich richten op veranderbare psychosociale risicomechanismen. Er is een duidelijke behoefte om deze programma's op een zodanige manier te implementeren dat ieder kind ervan kan profiteren. Hetzelfde geldt voor hun ouders.

Dit proefschrift geeft aanbevelingen voor de inhoud en de organisatie van de steun en het onderzoek dat verdere ontwikkelingen en implementatie vergezelt. Nu is het nodig dat hulpverleners en ouders constructief en in openheid samenwerken, terwijl ze gebruik maken van elkaars krachten en luisteren naar hoe mensen met of zonder succes de problemen het hoofd bieden. Onderweg valt meer te leren dan we aan kennis kunnen meenemen als we aan een reis beginnen.

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# APPENDIX 1

## PARENTING WITH SUCCESS AND SATISFACTION. *A REHABILITATION INTERVENTION FOR PARENTS WITH SEVERE MENTAL ILLNESS.*

Van der Ende, P.C., Venderink, M.M., Busschbach, J.T. van (2010). Parenting with success and satisfaction. A rehabilitation intervention for parents with severe mental illness. *Psychiatric Services 61*:416.

Always a complex and demanding task, parenting can be an extra challenge when parents have severe mental illness. They may experience extra stress, feelings of uncertainty, and a lack of energy. They may have difficulty in talking about their disabilities with their children. Often, there are struggles with limited material resources and stigma or grief over the loss of having direct custody of their children. In all these situations, clients need support in interacting and communicating with their children in ways that benefit both parties.

However, although there is a growing awareness of the needs of these clients and of parental responsibility for the children involved, the parental role is seldom a topic in mental health care. Within the field of rehabilitation, although there is considerable professional literature on skills training and experience in helping clients to realize personal goals in the areas of work, education, living arrangements, and social contacts, there are few or no tools to support clients who wish to strengthen their parenting skills.

When we, as workers trained in individual rehabilitation, were confronted with this gap, we set up a program that is called Parenting with Success and Satisfaction. The aim was to enhance the "choose-get-keep" model of psychiatric rehabilitation by adding new components about parenting.

We conducted a survey of clients' needs for support in their parenting. In this survey 47 persons (41 mothers and six fathers) participated, and 28 were single. Eighty percent (N=38) felt that their psychiatric problems interfered with the relationships they had with their children. Although almost all (N=44) said that they received enough professional care, half of them wanted forms of support that regular mental health care did not supply: practicing ways of entering into a conversation with the child, support in dealing with the child, nurturance support, legal assistance with custody and child support, and help in arranging support from peers. Those with no direct responsibilities in raising their children (N=9) wanted more and better contact with them. For all, an important issue was finding a good match between being a parent and creating a life for themselves within the constraints that come from psychiatric illness.

From these results a support program was further developed with the concept of empowerment as the starting point. Three workbooks were written to help clients achieve their parenting goals. The first workbook focuses on assessing skills and opportunities as a parent. For example, clients examine how to divide their time and attention between everyday roles and parental activities. The second workbook aims at strengthening the parenting role. Questions deal with what parenthood means for the individual and how, in a given context, one can function as a parent successfully and with satisfaction. With the third workbook, clients can work on renewing or expanding the parenting role. This last workbook is intended for parents who temporarily have no direct parental caretaking responsibilities.

In the program, parenthood is seen as a valued social role that individuals model in their own ways. There is an explicit awareness of and respect for both the needs of

the children and the choices and constraints of their parents. Throughout the program attention is paid to communication with others who are involved with the child, such as grandparents, step-parents, friends, and professionals. They can be a resource of extra help and positive emotional support as well as a resource of constructive criticism to ensure that children get what they need.

Clients progress through the workbooks with a rehabilitation worker in ways that are adapted to their own situations and preferences, both individually or in groups. In individual contacts, working on parental goals can be combined with working on other goals. If contact between a worker and a client has a single emphasis on the parental goals, the whole program takes about a year on average with weekly sessions. Before entering the program, clients are informed of this commitment. Parents may fear seeking support because of concern about custody loss, and this concern is discussed before entering the program.

# APPENDIX 2

## *OUTLINE OF THE PROGRAM*

## "PARENTING WITH SUCCESS AND SATISFACTION (PARSS)"

The program Parenting with Success and Satisfaction PARSS gives tools to the mental health practitioner to coach parents during a short or long period in their parental role. It is for parents with daily care and responsibility for education for their children and also for parents that see their child once in a while because of an arrangement concerning parental access.

## Principles behind the program

The Parenting with Success and Satisfaction (PARSS) intervention is based on: (a) the psychiatric rehabilitation framework (Farkas & Anthony, 1991); (b) a focus on enhancing self-regulation (Sanders & Mazzucchelli, 2013); (c) structured strategies for proactive service to reach out to parents who express a need for support rather than waiting for a problem or crisis to occur (Weir, 2004); and (d) a transdiagnostic approach that suggests that certain fundamental processes underlie or transcend multiple psychiatric diagnoses.

In the PARSS intervention, parenting is seen as a valued social role that is defined by individuals in their own way. There is an explicit awareness of and respect for both the needs of the children, and the choices and constraints of their parents. Emphasis is placed on communicating well with others who are important to the parent and the child. Attention is also paid to effective communication with more formal sources of support, such as school personnel or representatives of agencies providing foster care to children. Parents may be reluctant to seek support from others—relatives or mental health practitioners —because they fear the negative attitudes and assumptions of others and possible loss of custody; this concern is discussed with parents before the start of the intervention.

## Workbooks

The PARSS intervention includes three workbooks for parents to help them achieve their parenting goals in a guided self-help approach. For parents, PARSS provides a way of working on self-selected goals for one's own well-being, in combination with a focus on the child's strengths and needs.

### Workbook I. Assessing functioning in the parental role

This workbook lays out explicit skills and recommended resources for carrying out the parental role for all parents. The chapters in this workbook are: Identity; Satisfaction and Success; Management of Time; Attention and Commitment.

The first issue in this book is to help the parent to reorientate on his-/her self, on the child and on the situation. When the psychiatric disorder of a person needs attention for a period the healthy, strong and normal parts of one's life receives than they really are.

The parent will be invited to think about several issues that come with parenting. These are worked out in the topics below and for every topic there are some exercises or assignments.

*Reorientation on yourself*

- What are your qualities, interests and values in life?
- What is important for you in raising your child?
- What are your strengths and vulnerabilities and how can you support yourself?
- What can other parents learn from you?

*Reorientation on the children, each child separately*

- Who and how is your child?
- What are your child's interests, what qualities and talents have your child?
- How does your child develop?
- What are the strengths and vulnerabilities of your child and how can you support it?
- Dividing your energy and time during the week
- What roles do you fulfil in life?
- How do you divide your time over your parent role and other roles?
- Is there enough energy to pay attention to yourself / do something relaxing?
- Satisfaction and success about parenting tasks and making connection with child and others
- How satisfied are you about your functioning, what are strong elements what should be strengthened?
- Who are important persons for you and your child?
- What do important others think about what is strong and should be strengthened in your functioning as a parent?
- Support, self-confidence and expectations
- Who supports you or who is working against you?
- Who might support you if he or she knows about you having a bad time in coping with your situation?
- How confident are you of being a parent?
- Are you able to ask for help or does that frighten you? (are you afraid of losing custody?)
- What are your expectations about the future as a parent?
- Do you think you can raise your child on your own or do you need others to receive support from?
- How do you see your future as a parent?

*Summary of the sessions*

What are your strengths and what are your weaknesses in fulfilling your role as parent.

What needs to be strengthened and what kind of support / help do you need right now?

To make a plan to develop and use skills / to develop and use resources can be done with the help of workbook IIa and IIb, which are both rehabilitation – oriented.

## Workbook IIa. Strengthening the parental role

With the help of this workbook, parents who are living with their children are encouraged to describe what the parental role means to them. Workbook sections include: What does the parental role ask of me? Do I meet these demands? Overcoming barriers. With this workbook the parent makes a plan to overcome the barriers in functioning as a parent.

*Demands that come with the parenting role*

- Who are important persons that can make demands of you as a parent?
- What demands do you make of yourself?
- Bottle-necks.
- What demands are a problem for you?
- Suitable solutions.
- What skills do you need to learn in order to meet the demands?
- What resources and support are available for you?
- Make a plan to strengthen the parenting role and schedule the activities you have chosen.
- Investing in contact.
- Communicate with others who are important to you and your child with what activities and actions you are strengthening your role as a parent.
- Make a plan together.

## Workbook IIb. Taking back or expanding the parental role

This workbook is designed for parents not living with their children but who want to expand their parenting role. This workbook is partly the same as the second workbook and can be used for a parent who is not in contact with her/his child at this moment; for example because the child lives with the ex-partner The workbook can also be used when a parent who has lost custody, does not have a visiting-arrangement with the child and would like to come in contact with the child. Or a parent who stays in mental health-center at this moment for treatment. Or the child lives with the ex-partner. It can also be used by parents who need to prepare on parenting after staying in the hospital (psychiatric episode) and by parents who want to expand their parenting role.

It focuses on exploring opportunities and situations specific to parents who live separately from their children. Based on the values and needs of the parent, opportunities and situations for dealing with the child are explored, particularly given that parents are not currently living with their children.

*The components are:*

- My needs as a parent;
- The possibilities for me as a parent;
- What is required for my choices?
- Can I meet the demands?
- Overcoming barriers;
- How to go on.

Parents in these kind of situations can be helped to make a restart by choosing an activity or defined situation. This can be done in cooperation with important others, so the parent needs to prepare only for a "small" part of all the parental tasks while others can take responsibility of the rest. This books starts with values, qualities and interests of the parent, earlier experiences and brainstorming possible activities and situations that could be a suitable context for the parent to meet the child and possibly also take care for the child.

In this book it is also an issue for the parent to become aware of the time and energy the parent can give to the child in order to make realistic choices.

The following parts of this workbook are the same as in the second book (Who demands? What demands? Your own demands? Can you meet the demands? Skills / resources / plan).

It ends with the importance of paying attention to staying in contact with important others and vice versa.

When the parent wants expansion of the parenting role in the future this workbook can be used again.

Parents progress through the PARSS Workbooks with a mental health practitioner in ways that are adapted to their own situations and preferences, individually or in groups. In individual contact, work on parenting goals can be combined with a focus on other goals. If contact between a practitioner and a parent has a single emphasis on parenting goals, the entire intervention takes about a year on average, with weekly sessions of one hour. Before beginning the intervention, parents are informed of this commitment. PARSS is relevant to parents who are raising their children themselves, or to parents who have contact with their children through a custody and visitation arrangement. PARSS may also be useful to parents during or after a psychiatric hospitalization.

Components of the intervention may be used by parents themselves as a self-help strategy. It is a kind of guided self-help. Other components of the intervention are best completed with the assistance of a mental health practitioner (i.e., a social worker nurse or psychologist and, in some cases, a psychiatrist). In PARSS the practitioner has a role as in other contacts with a rehabilitation goal. The aim is to develop a positive relationship in which listening skills, empathy and a client-centred attitude facilitate the parent to set one's own goals and stimulate self- efficacy. Mental health practitioners

offer support and help to train skills, enhancing hope and positive expectations about the future. They have an active role: they help parents to explore their needs where the parental role is concerned and on an organizational level also ask for attention and facilities for supported parenting. In the workbooks continuously attention is paid to the communication with relevant others who are important to the parent and the child and establish a functional dialogue. This can be personal contacts of the parent but also professionals in the situation by an official reason (foster-organization, foster-parents, school, etc.). It is important to help the parent to communicate with others because they can help the parent to focus on the needs of the child.

Based on this program also a group program is developed with the same structure.

## Training of mental health practitioners

The training of mental health practitioners to implement PARSS takes a total of 4 days, with longer intervals between sessions in the last phase of training to facilitate clinical supervision.

The training is aimed at mental health practitioners from organizations that already work with psychiatric rehabilitation. It is important that the mental health practitioners can practice with patients between the training sessions.

# CURRICULUM VITAE

Peter van der Ende is in 1952 in Maasdijk (gemeente Naaldwijk, nu Westland) geboren in een tuindersgezin. Zijn ouders hadden vier dochters en twee zonen. Hij volgde zijn middelbare schoolopleiding 15 kilometer verderop, in Vlaardingen aan het Groen van Prinsterer Lyceum. In 1971 behaalde hij het diploma H.B.S.-b. Hierna koos hij voor de studie Psychologie in Leiden. In die periode was hij ook werkzaam bij Release Leiden, een organisatie die mensen steunde die in moeilijkheden waren of dreigden te geraken doordat hun rechten of vrijheden werden aangetast. Zijn doctoraalstudie bestond uit Klinische Psychologie, met als bijvak Methoden en technieken van onderzoek en als nevenvak Sociale geneeskunde ( bij prof. dr. C. Trimbos te Rotterdam). Zijn eindscriptie had als titel:

*Komt tijd, komt raad*? *Een onderzoek naar het uitstellen van een huisartsconsult bij psychische klachten*. Na verschillende werkzaamheden bij de Leidse universiteit en bij hulpverleningsinstellingen, vertrok hij met zijn vriendin en latere vrouw, Loes Verhoef, naar Leeuwarden om in de ambulante verslavingszorg, bij het Consultatie Bureau voor Alcohol en Drugs, te werken als coördinator Hulpverlening.

Het onderzoek bleef trekken en daarom solliciteerde hij naar : onderzoekersfunctie op de afdeling Sociale Psychiatrie te Groningen (met prof. dr. R. Giel als hoofd). Daar heeft hij drie jaar onderzoek gedaan naar codering- en classificatiesystemen in de psychiatrie. In 1990 ging hij verder in het onderzoek, en wel in de gerontologie bij het Gerontagogisch Centrum Groningen van de latere Hanzehogeschool Groningen. Hij voerde daar verschillende onderzoeksprojecten uit bij verpleeghuizen, verzorgingshuizen en het grijze gebied daartussen. Deze onderzoeken werden afgewisseld met onderwijs en onderwijsontwikkeling bij de opleiding Sociaal Pedagogische Hulpverlening (SPH).

Vanaf 2003 is hij senior onderzoeker bij het lectoraat Rehabilitatie van de Hanzehogeschool Groningen, waar dr. E. L. Korevaar  lector is. Naast zijn onderzoek heeft hij zich ook bekwaamd in de methodiek Individuele Rehabilitatie Benadering (IRB) en hierin de praktijk mee gewerkt. Voorafgaand aan zijn promotieperiode heeft hij meegewerkt aan de door Marrie Venderink van Lentis ontwikkelde methodiek Ouderschap met Succes en Tevredenheid (OST). Hiernaast deed hij onderzoek naar ondersteuningsgroepen van studenten met psychische beperkingen en de implementatie van de IRB. De rode draad in zijn ontwikkeling is steeds weer het steun geven aan kwetsbare mensen. Het hier gepresenteerde promotieonderzoek is verder gegaan in die lijn. Het ouderschap van ouders met psychische aandoeningen krijgt niet vaak aandacht. Dit proefschrift maakt de contouren voor het eerst zichtbaar.

*Website project: http://www.ouderschap-psychiatrie.nl*

*Publicaties zie http://www.pcvanderende.nl*

# NAWOORD

**RING THE BELLS THAT STILL CAN RING**
**FORGET YOUR PERFECT OFFERING**
**THERE IS A CRACK IN EVERYTHING,**
**THAT'S HOW THE LIGHT GETS IN**
**THAT'S HOW THE LIGHT GETS IN.**

**"ANTHEM" , LEONARD COHEN**

Psychologie en psychiatrie hebben mij mijn hele leven geïnteresseerd. Uit de onderzoeksprojecten binnen deze onderwerpen en uit eigen ervaring weet ik dat psychische aandoeningen stigmatiserend kunnen zijn. Stigmatisering geldt mogelijk ook voor de ouders in de deelonderzoeken van dit proefschrift. Het kostte soms enige moeite om hen te betrekken bij de onderzoeken omtrent ouderschap, maar als het contact eenmaal tot stand was gebracht, volgde daarna vrijwel altijd een open gesprek. Aan de ouders die op deze open manier hebben verteld waar hun mogelijkheden en tekorten lagen op het terrein van ouderschap, is dit proefschrift gewijd en hierbij dank ik hen voor hun inzet. Via vele contactpersonen binnen de geestelijke gezondheidszorg en de ziekenhuizen ben ik met deze ouders in contact gekomen. Daarnaast hebben wij ook interviews gehouden met hulpverleners en met naastbetrokkenen familieleden en vrienden van de betreffende ouders. Ik heb er veel waardering voor dat zij hiervoor hun tijd beschikbaar stelden.

Met Loes, de liefde van mijn leven, heb ik ook in deze promotieperiode alles gedeeld. Na mijn tegenslagen was ze extra lief voor mij, en ook besteedde ze steeds aandacht aan de successen. Bij elk onderzoek zijn er immers meestal drie markeringspunten: de goedkeuring/subsidie van het onderzoeksvoorstel, de afronding van het onderzoek en het accepteren van een publicatie. Al deze mijlpalen wist ze altijd nog vrolijker te maken.

Mijn ouders zouden op hoge leeftijd zijn geweest als zij nog in leven waren. Dat ze nu al ruim 35 jaar geleden zijn overleden, wil niet zeggen dat ik ze niet mis. Dit geldt met name bij belangrijke levensgebeurtenissen, zoals deze promotie.

Zus Jacky heeft me gedurende haar hele leven vergezeld en was altijd dichtbij in een fijne zus-broerverhouding. Dat zij me tijdens de promotie steunt als paranimf, is een mooie illustratie van de geschiedenis die we met elkaar hebben. De andere paranimf, Jannie Boomsma, laat zien wat een fijne collegiale vriendschap inhoudt. Nu ze als collega verder weg is, blijft de vriendschap in stand.

Vanuit de tijdstippen van de correcties van mijn concepten en van haar e-mails viel af te lezen dat de begeleiding van mijn promotie als copromotor door Jooske van Busschbach regelmatig buiten kantooruren viel. Ze is van het begin tot het einde intensief betrokken geweest bij deze promotie. De voltooiing van de promotie was niet gelukt zonder al die anderen, en zonder haar zeker niet.

Een tijdlang had ik al de overtuiging dat men andere mensen niet kan veranderen. Ook in de hulpverlening kan alleen een zelfgekozen verandering plaatsvinden. Psychosociale (of psychiatrische) rehabilitatie heeft dat als uitgangspunt en dat was een *eyeopener* voor mij. Allerlei andere hulpverleningstechnieken, waarbij de kennis en kunde van de hulpverlener vooropstaan, verdwenen voor mij naar de achtergrond. Het enthousiasme waarmee Lies Korevaar rehabilitatie, participatie en herstel vormgeeft, heeft voor mij aanstekelijk gewerkt. Hij was het ook die samen met Marrie Venderink het onderwerp ‘begeleid ouderschap bij psychische aandoeningen’ na een congres in Amerika naar Nederland bracht en op mij overdroeg. Hij gaf me als leidinggevende

en als copromotor veel ruimte om in eigen tempo en op een eigen manier mijn werk te doen.

Jaap van Weeghel kwam als promotor later in dit promotietraject en wist het om te buigen van een kwantitatief naar een meer kwalitatief onderzoek. Hij getuigde iemand te zijn van de grote lijnen, waarbij ook de details niet werden vergeten. Waar hij de tijd vandaan haalde om binnen een week op mijn conceptartikelen te reageren, is voor mij een vraag, maar voor hem een weet. Dat kwalitatief onderzoek goed aansluit bij vele praktijkproblemen in de gezondheidszorg, is inmiddels goed tot mij doorgedrongen.

Promotor en copromotoren: bedankt voor jullie inzet en geloof in mijn mogelijkheden om de promotie tot een goed einde te brengen.

Joanne Nicholson stimuleerde mij niet alleen in een vroege fase van de nieuwe media tot het gebruik van Facebook en Skype, maar gaf ook betekenis aan de communicatie via die kanalen. Via dit werk heb ik haar enkele keren kunnen ontmoeten en dat heeft een positieve bijdrage aan mijn ontwikkeling gegeven. Dat Joanne uiteindelijk coauteur is geworden van twee artikelen, heeft niet alleen te maken met haar inzet daarvoor, maar ook met haar inspirerende betrokkenheid bij het onderwerp van dit proefschrift.

In de beginfase van het project reikte Durk Wiersma ideeën aan voor enkele onderdelen van dit proefschrift. Mede door zijn scherpe analyse van de materie zijn die onderdelen ook succesvol omgezet in gepubliceerde artikelen.

Eerdergenoemde Marrie Venderink ontwierp met enthousiaste en kundige inzet, door mij en enkele anderen gesteund, de rehabilitatiemethodiek Ouderschap met Succes en Tevredenheid. Dit is één van de steunpilaren van dit proefschrift geworden. Hanny van Asdonck maakte mij via een college enthousiast voor het onderwerp rehabilitatie en Franca Hiddink bracht mij de beginselen van de Individuele Rehabilitatie Benadering bij. Met Jannie Boomsma werkte ik samen aan enkele projecten, en de andere collega's van het lectoraat Rehabilitatie wisselden hun ervaringen en kennis van de verschillende rehabilitatieprojecten gul met mij uit. Karola Nap, management-assistent van het lectoraat Rehabilitatie, bleek op vele terreinen thuis te zijn of werkte zich snel in op nieuwe terreinen (zoals gegevensinvoer in SPSS). Met Charlotte de Heer-Wunderink deel ik de laatste jaren een werkkamer en met haar ervaar ik wederzijdse steun in het werk en ook in familieaangelegenheden. Bedankt, collega's, voor deze samenwerking. Boeiend was het ook om gezamenlijk congressen te bezoeken in onder meer Utrecht, Geel (B.), Athene, Boston en Kaapstad.

Mijn dank gaat ook uit naar studenten en collega's die essentiële bijdragen hebben geleverd aan verschillende onderdelen van vier onderzoeken, onder meer door interviews: Sietske Lenting & Alies Soepenberg, Annette Bloemen, Damiët de Bruin, Henk Dijkstra & Marijke Ringersma, Wilma Steijn, Anja van den Bosch, Saskia Drager & Jenny Kroon, Ypie Godlieb, Loes Roorda, Merije van Dam & Gaby Timmer, Elke Duppen & Rianne Stevens, Marianne van den Berg & Evelien Sulmann, Rindert Scheper, Inge Sloots, Ingrid de Vries, Stefanie Eigenraam, Daphne Wind, Léonie de Vries, Sanne van

Eeden, Antoinette Kloosterman, Leonie Werkman, Leonie Bulthuis, Evelien Hoekstra, Anneloes Praamstra & Loes Schoonenboom, Marieke van Lottum, Annemiek Buzeman, Janine van Ritbergen, Tanja Gosink, Mariëlle Dullemond & Wendy van der Veldt en last but not least: Aimée de Jong, die interviewer was bij verschillende onderdelen.

Louis Polstra, Henny Oosterbaan, Annemarie Schoonhoven en Heleen Smeets leverden hun waardevolle bijdragen aan het onderzoek naar ouderschapsstrategieën van ouders met psychische aandoeningen (hoofdstuk 4). Ariëtte Hennemann, Marion Troia, Annemartha Zimmerman en Wiley editors service zorgden voor correcties van de Engelse tekst van verschillende artikelen. Ik ben blij dat zij het Engels dusdanig verbeterden, dat de artikelen werden geaccepteerd in internationale peer-reviewed tijdschriften.

Sinds 1979 had ik de titel “doctor in wording” (doctorandus). Het leek mij een te grote inspanning om naast mijn werk nog eens een promotietraject in te gaan. Na de afronding van het project “Steun voor ouders met psychiatrische beperkingen”, dat Marrie Venderink en ik met een rapport, een begeleidingsmethodiek en een goed bezochte studiedag afrondden, veranderde dit idee. De toenmalige dean van de Academie voor Sociale Studies, Han de Ruiter, bood me aan om één van de vijftig door de Hanzehogeschool gesubsidieerde promotieplaatsen in te nemen. Ik kon er niet meer omheen om dit onderwerp verder te ontwikkelen. Zijn opvolgster, Michèle Garnier, heeft de voortgang van het promotieproject gestimuleerd. Dat er voor dit proefschrift uiteindelijk vijf verschillende onderzoeken zijn gedaan, die zijn uitgemond in vijf artikelen, die in wetenschappelijk tijdschriften zijn gepubliceerd, heeft ervoor gezorgd dat het een tijdrovende zaak werd.

De Hanzehogeschool heeft veel geboden aan tijd en faciliteiten om deze promotie mogelijk te maken. Dat er ook een fitnessruimte vlakbij mijn werkplek is en dat door Hanzefit vormen van ontspanning/concentratieoefeningen onder meer via mindfulness worden geboden, maakt deze organisatie tot een modelwerkgever.

De opleiding Sociaal Pedagogische Hulpverlening en later ook de Academie voor Sociale Studies hebben mij meer dan 25 jaar een basis gegeven voor het werken met studenten en met collega’s. Ook na talloze wisselingen van collega’s is dit nog steeds de werkomgeving waarin ik mij thuis voel en waar ik visies en meningen op een prettige manier kan uitwisselen.

Voor een deelonderzoek (hoofdstuk 4) heeft het Fonds Psychische Gezondheid een subsidie gegeven. Het uitgangspunt van deze organisatie, namelijk mensen met psychische problemen en hun naasten uitzicht te bieden op een beter leven en betere behandelmethoden mogelijk te maken, sluit naadloos aan bij de inhoud van dit proefschrift. Ik ben hun en hun donateurs dan ook zeer erkentelijk voor hun financiële bijdrage.


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